PEI PAP SCREENING PROGRAM

2001 Report

May 2002

Prince Edward Island
CANADA

Epidemiology Unit
Health and
Social Services

PEI Pap Screening Program
Program Coordinator - Heather MacMillan
2nd Floor Jones Bldg., 11 Kent Street
PO Box 2000, Charlottetown, PE C1A 7N8
Phone: 902-368-4951
Fax: 902-368-4969
E-mail: hmmacmillan@gov.pe.ca

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Epidemiology Unit, DHSS
PEI Pap Screening Program Advisory Committee

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Acknowledgments

The PEI Pap Screening Program would like to thank its partners, the PEI Division of the Canadian Cancer Society, the Medical Society of PEI, PEI Women's Network and the PEI Department of Health & Social Services, who have supported and contributed to this program.

The success of the PEI Pap Screening Program also depends on an integrated system of health professionals taking the Pap smears, dedicated and trained staff to process and read the slides as well as medical specialists to provide colposcopy and treatment follow-up. Thank you.

Thanks also to the NS Gynaecological Cancer Screening Programme for support during the development of the program, including the use of the "Pap Screening for Life" logo. Also thanks to Western Newfoundland for their input and sharing of information.

Executive Summary

Over 90% of cervical cancer can be prevented by regular screening with the Pap test. In spite of access to the Pap test since the 1960's, the incidence of cervical cancer has been increasing in PEI, in contrast to the declining Canadian rate. Most cases of cervical cancer occur in women not regularly screened. This highlights the need for a more organized approach to cervical cancer screening in PEI.

Prior to the formal establishment of the PEI Pap Screening Program in 2001, much effort had gone into developing the groundwork for an organized screening program. This work was a prelude to the January 16, 2001 inaugural meeting of the Pap Screening Advisory Committee, a multi-disciplinary group to oversee the diverse responsibilities and interests in cervical cancer. The PEI Pap Screening Program's goal is to reduce the incidence and mortality from cervical cancer among Island women.

Highlights of the activities in the PEI Pap Screening Program's first year include the Pap Screening Clinic, Pap Awareness Week, and reporting on program indicators.

The Pap Screening Clinic was launched September 6, 2001 in Cornwall, PEI. The goal of the clinic is to increase the number of women regularly screened with a Pap test by providing an alternative service to increase accessibility. The clinic's trained registered nurse provides Pap tests under the supervision of Dr. DI Stewart. Over the period September to December 2001, 477 women had a Pap at the clinic. The majority of the women attending the Clinic were overdue for Pap screening: 75% of the women attending had their last Pap two or more years ago.

PEI's second Pap Awareness Week campaign was held October 20 to 27, 2001. This campaign resulted from coordinated efforts with campaigns in Nova Scotia and Newfoundland, the implementation of a PEI marketing strategy, and the evaluation of PEI's 2000 campaign. The main focus of this campaign was to increase awareness that cervical cancer can be prevented by regular Pap tests. The key messages were delivered using a media blitz and promotional materials that maintained the visual identity of PEI's 2000 campaign.

The program indicators available in this report are statistical measures of program performance that can be used to inform policy decisions, and to assess program effectiveness. The PEI Pap Screening Program encourages regular screening at least every two years. PEI's overall two year screening rate during 2000-2001 for women aged 20 to 69 was 58%.

Future challenges for the PEI Pap Screening Program include continuing the development towards an organized provincial screening program, with an emphasis on increasing regular Pap screening.

Table of Contents

1. Introduction 2
   - 1.1 Cervical Cancer
   - 1.2 National Background
   - 1.3 PEI Background

2. Organized Cervical Cancer Screening Programs 5
   - 2.1 International Programs
   - 2.2 National Recommendations
   - 2.3 Provincial Screening Activity

3. PEI Pap Screening Program 8
   - 3.1 Program Structure
   - 3.2 Program Goals

4. Program Indicators for PEI Pap Screening 10
   - 4.1 Participation Rates for PEI
   - 4.2 Specimen Adequacy
   - 4.3 Cytology Results
   - 4.4 Follow-up Recommendations
   - 4.5 Incidence of Cervical Cancer
   - 4.6 Mortality of Cervical Cancer

5. Program Activities in 2001 16
   - 5.1 Pap Awareness Week
   - 5.2 Pap Screening Clinic
   - 5.3 Cytology Laboratory
   - 5.4 Screening Guidelines
   - 5.5 Performance Indicators

6. Future Challenges 20

7. Appendices 21
   - A Recruitment Strategies
   - B Liability for Follow-up
   - C Profile of Unscreened Women
   - D Well Woman Clinics
   - E Understanding the Barriers to Cervical Cancer Screening in PEI
   - F 2000 PEI Pap Awareness Campaign
   - G Terms of Reference - Advisory Committee, Working Groups
   - H Detailed Data for Program Indicators
   - I Minimum Data for Cytology Registry
   - J Cytology Registry Upgrades
   - K Pap Screening Clinic

1. INTRODUCTION

The purpose of this report is two-fold: to document the activities leading up to the establishment of a provincial Pap Screening Program; and to provide a report on the activities occurring in the first year of the program from January 1, 2001 to December 31, 2001.

The PEI Pap Screening Program's goal is to reduce the incidence and mortality from cervical cancer among Island women. The Program encourages regular screening for cervical cancer.

1.2 Cervical Cancer

The cervix is the lower part of the uterus, and is found at the top of the vagina. The cells covering the cervix can become malignant (uncontrolled cell growth), causing cervical cancer. Cervical cancer is slow to develop. It generally develops before the age of 70; the average age of diagnosis is 45 years. The cells of the cervix go through mild to severe changes over a period of years before the cells change to cancer. At the early stages of these changes, there are no signs or symptoms. However, the early cell changes can be detected and treated before cancer develops. Over 90% of cervical cancer can be prevented by regular Papanicolaou (Pap) tests.

The Pap test is a simple and effective procedure for detecting precancerous conditions. Since the Pap test was introduced 40 years ago, deaths from cervical cancer have declined. In Canada, the incidence of cervical cancer declined 50% between 1969 and 1990; deaths dropped by two-thirds. However, in the last ten years, the decline has leveled off, suggesting that the current ad hoc approach to screening which is termed opportunistic, has reached its potential.

Currently in Canada, most Pap tests are performed in physician offices. Access relies on the individual woman's and/or her health practitioner's initiative. Opportunistic screening has a number of limitations including limited ability to identify and recruit women who are at highest risk of developing cervical cancer - those who have never had a Pap smear or do not have them regularly. Another limitation is the lack of coordinated efforts for public and professional education about cervical cancer screening. Coordinated efforts are also conducive to quality improvement in the collection of Pap smears, laboratory activities, and follow-up and treatment of abnormalities.

A reduction in mortality from cervical cancer is best achieved through an organized provincial screening program. Efforts to develop province-wide screening programs have been underway for several decades.

1.2 National Background

In Canada, numerous recommendations have been made over the past 25 years to develop organized approaches to cervical cancer screening. This includes the Canadian Task Forces in 1973, 1982, and 1989.

In 1995 the Cervical Cancer Prevention Network (CCPN) was formed. This is an informal network of federal, provincial/territorial and professional societies established to foster the development of organized provincial cervical cancer screening programs in Canada. CCPN has hosted meetings for information exchange, and produced resources including a summary of recruitment strategies (see Appendix A), guidelines for screening[1], and a surveillance report not yet released.

Interest in organized screening programs was also inspired in the spring of 2000 by publicity of a Manitoba woman who died with cervical cancer. The woman had a pap test that indicated severe cellular changes. The follow-up biopsy and treatment occurred more than one year later when the patient returned with symptoms. Both the hospital and the doctor were found legally liable for not having a system in place to monitor cytology results (details in Appendix B).

Over the past 25 years, pap screening has been a successful public health measure, with a 50% decline in the mortality from cervical cancer in Canada. However, in the last ten years, the decline has leveled off, suggesting that the current approach to screening has reached its potential.

1.3 Prince Edward Island Background

In spite of some national success with cervical cancer, Prince Edward Island has not demonstrated any declines. PEI consistently has one of the highest rates of cervical cancer in Canada (see Sections 4.5, 4.6). Most cases occurred in unscreened or inadequately screened women[2].

In October 2000, Minister of Health and Social Services, Honorable Jamie Ballem, announced the establishment of the PEI Pap Screening Program, with the primary goal of reducing the incidence and mortality rates associated with cervical cancer in PEI.

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1 Programmatic Guidelines for Screening for Cancer of the Cervix in Canada. Quality Management Working Group, CCPN. Health Canada: 1998.

2 Sweet et al. Review of Cervical Screening History of PEI Women. Chronic Dis Can 1991; 12(1): 1-3.

Prior to the formal establishment of the PEI Pap Screening Program in January 2001, much effort had gone into developing the groundwork for an organized screening program. Following is the PEI activity prior to 2001:

- 1967 PEI physicians provide pap screening to women
- 1991 Review of 54 cervical cancer cases showed the majority had not been screened in three or more years prior to their cancer diagnosis
- 1993 Survey of women (2,000 WI members) indicate 90% considered a notification letter an acceptable invasion of their privacy
- 1996 QEH Laboratory implemented LCMS software to capture all cytology and histology data
- 1997 Research to describe unscreened women (see Appendix C) found:
  - 60% of Island women are screened every 3 years
  - 40% of Island women are screened every year
- 1998 Well Woman Clinics were piloted across PEI by the Well Women's Health Coalition (see Appendix D).
- 1999 A Social Marketing Plan was developed to seek provincial support for a major public education program to increase the number of women aware of the importance of regular screening
- 2000 Research on the barriers to screening (see Appendix E) found:
  - Resistance to request a pap test
  - Low value for preventive care
  - Misconceptions of preventability of cervical cancer, role of family history, recommended ages for screening
- 2000 Pap Awareness Campaign in 4th week of October, along with NS and NF. The campaign included a media blitz and promotional materials (see Appendix F). The key messages for this campaign:
  - cervical cancer can be prevented
  - a pap test every 2 years can save your life
  - call your family physician for an appointment today

2. ORGANIZED CERVICAL CANCER SCREENING PROGRAMS

2.1 International Programs

Several countries provide existing examples of organized screening programs.

The Australian program uses a recall period of every 2 years. The program sends letters of recall directly to women who registered at time of their previous pap. The program recorded 64% of women (20-69) screened in the 2 year interval 1997-98.

The program in the United Kingdom uses a recall period of every five years. The program sends letters of recall directly to women who register at the time of their previous pap. The program also provides doctors with incentives for collecting Pap tests. The program recorded 85% of women (25-64) screened in the 5 year interval 1993-97.

The program in Iceland used a recall period of every 2 years, and is currently reviewing the use of longer recall periods. The program relied on the encouragement of physicians until 1997, when central coordination began to send letters of recall directly to women. The program recorded 37% of women (20-69) were screened in 1996.

Finland has had a program for the past 30 years that provides women aged 30 to 60 years with an invitation to be screened every five years.

2.2 National Recommendations

In Canada, numerous recommendations have been made over the past 25 years to develop organized approaches to cervical cancer screening. Organized programs for cervical cancer screening would increase the efficiency of screening, and enhance the management of abnormal tests. An organized screening program meets the following criteria: [3] [4]

1. Organization
    - Facilities for performing tests, diagnoses, and treatments
    - Program structure and coordination
    - Referral system
    - Funding

---

[3] Interchange 95 Cervical Cancer Screening Workshop, CMAJ 1996: 154(12) p. 1847-1853.

[4] Hakama, Chamberlain, Day et al. Evaluation of screening programs for gynaecological cancer. British Journal Cancer 1985; 52: 669-6734

2. Information Systems
    - Cytology database to provide screening history for each woman
    - Histology database to provide diagnostic information
    - Colposcopic database to provide follow-up information
    - Recall system to doctors for overdue pap tests
    - Linkage with population registry for recruitment

3. Quality Assurance
    - Guidelines for screening, identify target population
    - Performance indicators for reports, ongoing evaluation and monitoring
    - Program follow-up of abnormal pap tests ("failsafe" mechanism)
    - Training standards, quality control
    - Treatment options

4. Education and Recruitment
    - Pap Awareness Campaign
    - Education for Professionals
    - Educational Resources
    - Recruitment initiatives for women not screened regularly, and for unscreened women

2.3 Provincial Screening Activity

Organized screening programs, as described above, are in various stages of development in the provinces. The well established programs are in British Columbia and Nova Scotia, with recent progress in many other provinces. Table 2.1 highlights the progress toward implementation of the components of an organized screening program. No province has all of the components in place.

In Prince Edward Island, some of the essential components in support of an organized screening program have been put in place. PEI has a centralized laboratory system with a computerized information system, a network of family physicians that provide "opportunistic" access to screening, and recently a Pap Awareness Campaign. The next step toward an organized screening program was to provide a structure to coordinate these diverse responsibilities, and to oversee the further development toward an organized cervical cancer screening program.

Table 2.1 Provincial Screening Activity, January 2001

SCREENING ACTIVITY	PEI	NS	NF	NB	QU	ONT	MAN	SASK	ALTA	BC
Organization: Program start date, Coordinator	2001 Heather MacMillan	1991 Margery MacIsaac	2002 planned Joanne Rose			1998 Maureen Cava	2000 Brenna Shearer-Hood		2000 Eileen Bell	1949 Dr. Jasenka Matistic
Information Systems: • Cytology database (provides ♀'s screening history)	✓ (1996)	✓ (1988)	✓ (3yr backlog)		Pilot in Montr (16labs)	1996-40% of paps 2000-85% of paps	Use MD billing			✓ (1976)
• Histology database (diagnosis linked with cytology)	✓ (Bethesda)	✓ (Walton)				(Bethesda)	(Bethesda)			✓ (Walton)
• Colposcopy data (follow-up linked with cytology)		✓ 1996-88%								✓
• Recall system to MD's for overdue paps		✓				(2001pilot-letters →MDs)				
• Population database (for individual recruitment)	✓	✓(1999 pilot-letters →♀)								
Quality Assurance: • Screening Guidelines	every 2 yr	annual	annual			every 2yr	every 2yr		annual	every 2yr
• Program Report including performance Indicators		✓	pilot			✓				✓
• Program follow-up of abnormal paps		✓ Letters to MD since'96								✓ Letters to MD
• Training Standards • Treatment Options										
Education and Recruitment: • Pap Awareness Campaign	✓(Oct 2000)	✓(Oct 1997)	✓(Oct 1999)			(Spring 2001)	✓			
• Education for Professionals		✓ Website				website				✓ BCCAgency website
• Educational Resources		✓	✓			✓			✓	
• Recruitment initiatives		-honorarium for WWC -reg. resource network	-5 PHN trained to provide paps -community facilitators			-Nurse pract. in N. Ontario -immigrant ♀			-peer educ. -minorities	-asian ♀ -aboriginal ♀ -correct. facility

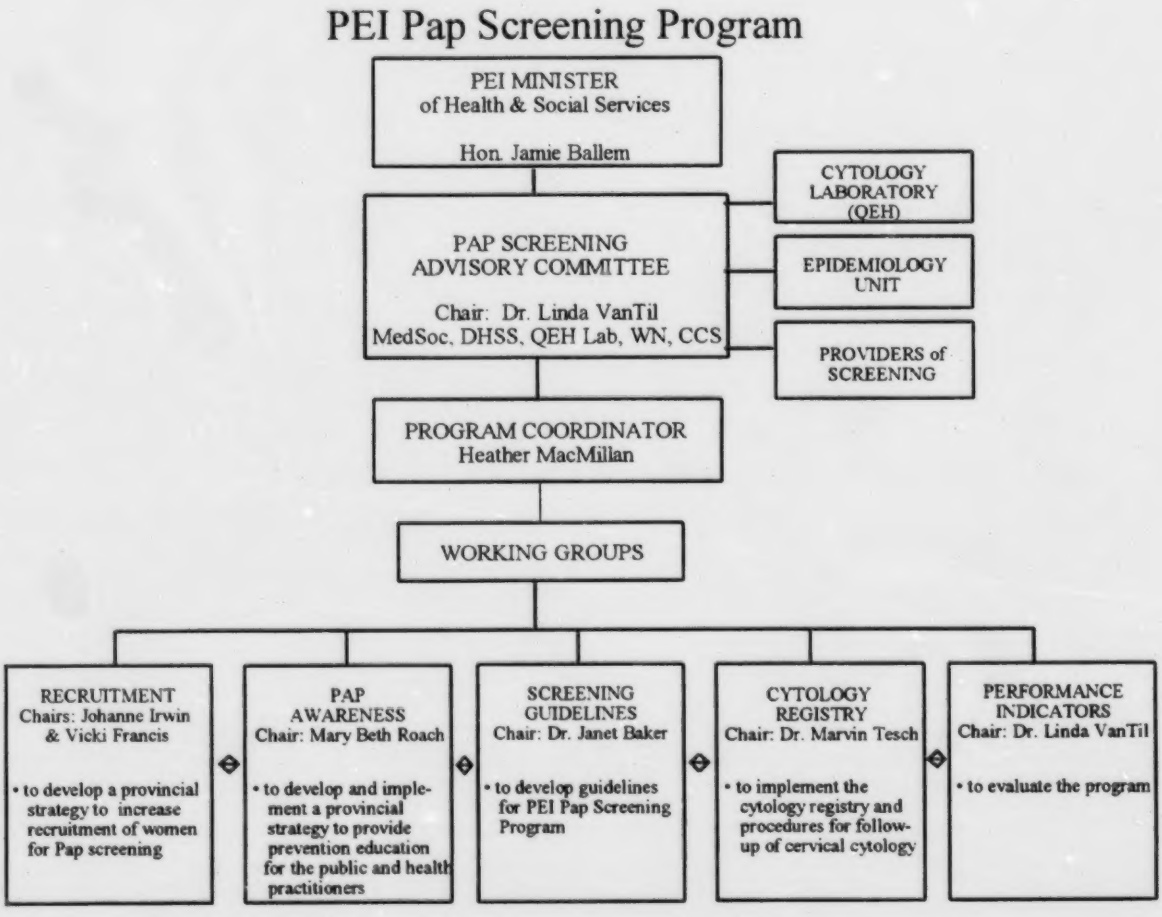
Source: CCPN Meeting, January 2001

3. PEI PAP SCREENING PROGRAM

The inaugural meeting of PEI Pap Screening Advisory Committee was held on January 16, 2001. Structure of the program as recommended by the Committee was approved by the Hon. Jamie Ballem, Minister of Health and Social Services, on March 21, 2001.

3.1 Program Structure

The program structure described below was designed to provide coordination to the diverse responsibilities and interests in cervical cancer, and to provide accountability.


PEI Pap Screening Program
PEI MINISTER
of Health & Social Services
Hon. Jamie Ballem
CYTOLOGY LABORATORY (QEH)
PAP SCREENING ADVISORY COMMITTEE
Chair: Dr. Linda VanTil
MedSoc, DHSS, QEH Lab, WN, CCS
EPIDEMIOLOGY UNIT
PROVIDERS of SCREENING
PROGRAM COORDINATOR
Heather MacMillan
WORKING GROUPS
RECRUITMENT
Chairs: Johanne Irwin & Vicki Francis
• to develop a provincial strategy to increase recruitment of women for Pap screening
PAP AWARENESS
Chair: Mary Beth Roach
• to develop and implement a provincial strategy to provide prevention education for the public and health practitioners
SCREENING GUIDELINES
Chair: Dr. Janet Baker
• to develop guidelines for PEI Pap Screening Program
CYTOLOGY REGISTRY
Chair: Dr. Marvin Tesch
• to implement the cytology registry and procedures for follow-up of cervical cytology
PERFORMANCE INDICATORS
Chair: Dr. Linda VanTil
• to evaluate the program

The Pap Screening Advisory Committee provides recommendations in the development, implementation, and direction of the PEI Pap Screening Program. Members include representatives from the Department of Health and Social Services, the PEI Breast Screening Program, the Provincial Pathology Laboratory, the PEI Division of the Canadian Cancer Society, the Medical Society of PEI, and the Women's Network. Program activities are carried out by many parts of the health system, with additional initiatives developed by working groups and overseen by the Pap Screening Advisory Committee.

The working groups established initially include the Recruitment Working Group, Pap Awareness Working Group, Screening Guidelines Working Group, Cytology Registry Working Group, and Performance Indicators Working Group. The Terms of Reference for the Advisory Committee and Working Groups are found in Appendix G.

3.2 Program Goals

As approved by the Pap Screening Advisory Committee on January 16, 2001, the goals of the PEI Pap Screening Program are:

- To reduce the incidence and mortality rates associated with cervical cancer in Prince Edward Island.
- To recommend appropriate practices covering all areas of an organized pap screening program which includes recruitment, screening guidelines, computerized cytology registry, quality assurance, evaluation, follow-up notification and educational resources.
- To identify and overcome barriers which prevent regular Pap screening among women in PEI and to identify and implement incentives which encourage regular screening.
- To increase public knowledge of the need for regular Pap tests as a preventative health care measure and ensure sustainability of Pap Awareness Week Campaign.
- To increase awareness among health professionals of the need for regular Pap smears as a preventative health care measure.

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4. PROGRAM INDICATORS for PEI PAP SCREENING

The program indicators available for this report are statistical measures of program performance. These indicators can be used to inform policy decisions, to assess program effectiveness, and to compare with other jurisdictions.

The indicators presented in this first report include:

- Provincial participation rates for PEI
- Specimen adequacy
- Cytology results
- Follow-up recommendations
- Incidence of cervical cancer
- Mortality of cervical cancer

Additional detailed data on the indicators presented in this section are found in Appendix H. The primary source of laboratory data is described in Appendix I.

4.1 Provincial Participation Rates for PEI

Participation in Pap screening programs are traditionally reported on an annual basis, to correspond with most physician recommendations. However, as organized screening programs are developing in Canada, there is interest in participation rates that correspond with provincial recommendations of every two years, and with national recommendations of every three years.

Table 4.1 provides the most recent provincial screening rates for all three screening intervals. These rates are monitored for women aged 20-69, since not all women under 20 or over 69 require screening. Table 4.1 also demonstrates that participation in Pap screening decreases with age, regardless of the screening interval.

Table 4.1 PEI Pap Screening Rates, periods ending 2001 (Population percent by age group)

	Screening Period		
Age group	One year (2001)	Two years (2000-2001)	Three years (1999-2001)
20 to 34	45 %	62 %	69 %
35 to 49	42 %	60 %	67 %
50 to 69	39 %	53 %	57 %
Total 20 to 69	42 %	58 %	65 %

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Figure 4.1 PEI Pap Screening Rates

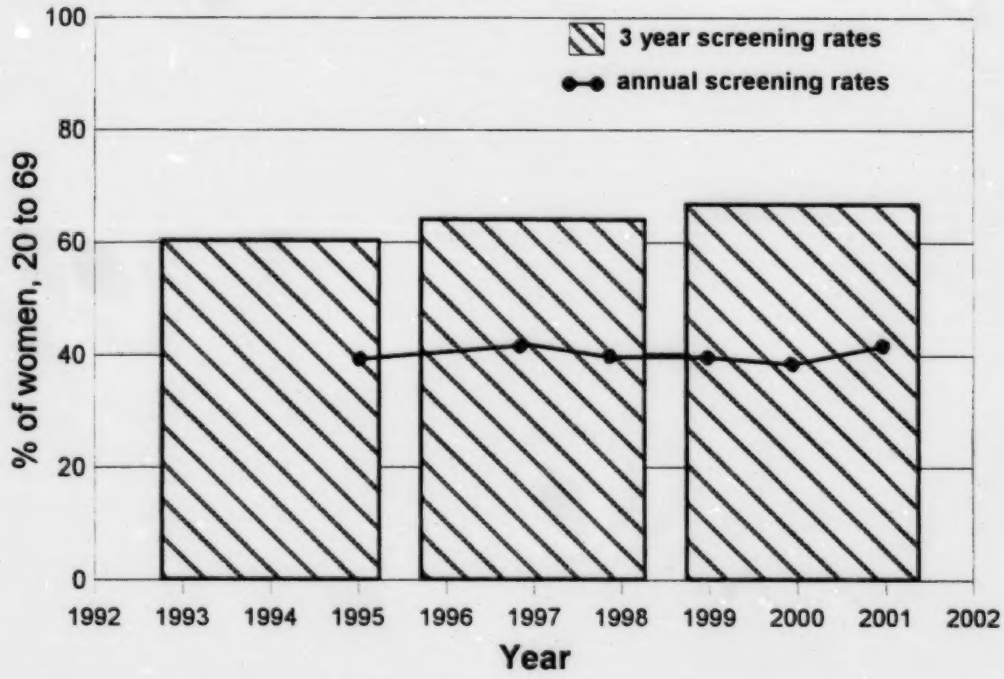


Figure 4.1 demonstrates the stability of PEI's annual screening rate. Each year, about 40% of PEI women between the ages of 20 and 69 were screened with a pap. This is similar to the rate described by Nova Scotia[5], where a program to increase screening was launched in 1991. British Columbia[6] has the oldest established program, but publishes 30-month screening rates.

Figure 4.1 also demonstrates the slight increasing trend in PEI's three year screening rates. In the most recent three year period, 65% of PEI women between the ages of 20 and 69 were screened with a Pap. This is similar to the rate described by Nova Scotia[5] for 1995 to 1997. Participation rates described in this report tend to be more accurate than rates from surveys asking women to self-report their most recent pap test (see Appendix C). Most surveys of self-report provide socially desirable responses that tend to over-report screening.

Participation in Pap screening on PEI is far from complete. To improve this, the Program will identify initiatives to increase regular screening of PEI women.

---

5 Statistical Report 1995 - 1997, NS Gynaecological Cancer Screening Programme, October 1999

6 2001 Annual Report, Cervical Cancer Screening Program, BCCA, 2001

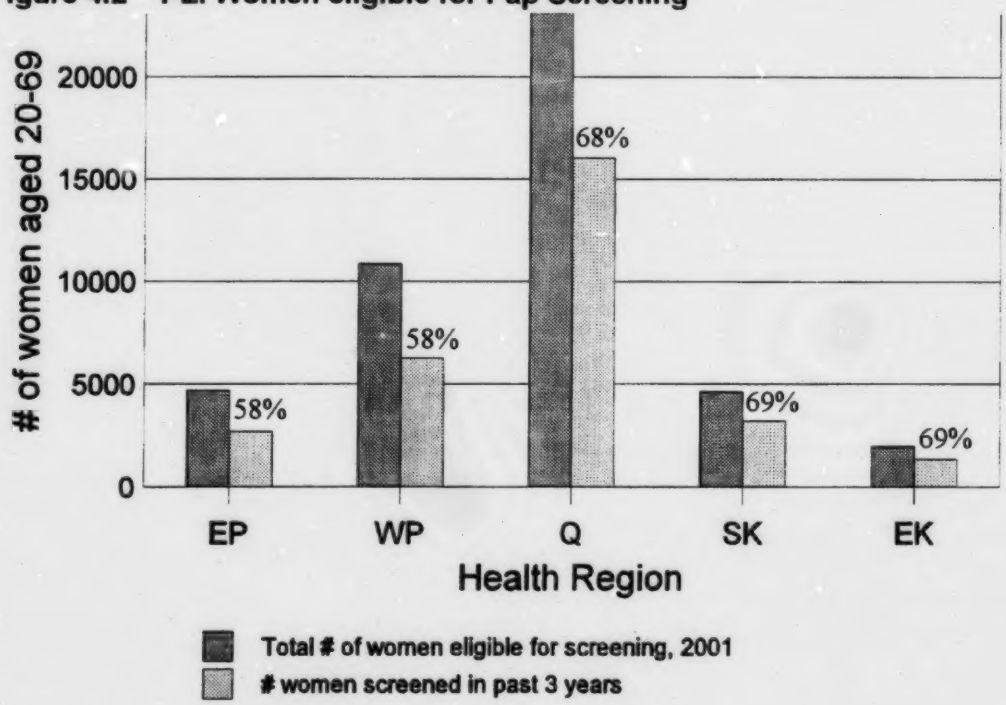
Table 4.2 demonstrates that participation in Pap screening varied by health region. The lower screening rates were seen in East Prince and West Prince. In all regions, the lowest screening rates are among women 50 and over. The screening rates in East and West Prince also show low rates among women aged 35 to 49.

Table 4.2 PEI Pap Screening Rates, 3 year period ending 2001 (by Health Region and age group)

	Health Region				
Age group	WP	EP	Q	SK	EK
20 to 34	70 %	67 %	70 %	71 %	74 %
35 to 49	59 %	59 %	70 %	73 %	70 %
50 to 69	44 %	46 %	63 %	64 %	64 %
Total 20 to 69	58 %	58 %	68 %	69 %	69 %
# unscreened women	1,971	4,566	7,580	1,442	615

Figure 4.2 provides a graphic depiction of the numbers of women eligible for screening and actually screened, demonstrating the gap of unscreened women that still need to be encouraged in all health regions.

Figure 4.2 PEI Women eligible for Pap Screening



4.2 Specimen Adequacy

Cervical smears are classified in the laboratory on the basis of their adequacy for interpretation: satisfactory, satisfactory but limited for interpretation, and unsatisfactory. Factors that limit the smear interpretation include blood, inflammation, poor fixation, contamination, or an inadequate number of cells. Table 4.3 demonstrates that 0.2% of smears were unsatisfactory for interpretation in 2001. This is similar to the 0.3% in Nova Scotia[5], and less than the 3% reported in British Columbia[6].

Table 4.3 PEI Specimen Adequacy, by year (Rate per 1,000 Pap tests)

	Year				
	1997	1998	1999	2000	2001
Satisfactory	847	834	843	850	872
Satisfactory, but limited	150	163	157	151	126
Unsatisfactory	2.8	2.5	0.7	1.3	2.1
Total # Pap tests	21,734	21,662	21,996	21,885	22,995

4.3 Cytology Results

The diagnostic results of all satisfactory smears are presented in Table 4.4 Diagnostic categories are based on the Bethesda classification. About 3% of Pap tests have a result that involves low grade or high grade cellular changes. This is similar to the 2% in Nova Scotia[5], and the 5% reported in British Columbia[6] and Ontario[7].

Table 4.4 PEI Cytology Results, 2001 (Rate per 1,000 Pap tests, by age group)

	Age Group			
Cytology Result	20 to 34	35 to 49	50 to 69	Total 20 to 69
Normal[1]	946	974	986	970
Low Grade Changes[2]	43	20	10	24
High Grade Changes[3]	9	4	3	5

[1] includes changes within normal limits and benign cellular changes
[2] includes LSIL, ASCUS, and AGUS non-suspicious
[3] includes HSIL, AGUS suspicious for malignancy, and carcinoma

[7] 2000 CytoBase Report, Insctye Corp. 2001.

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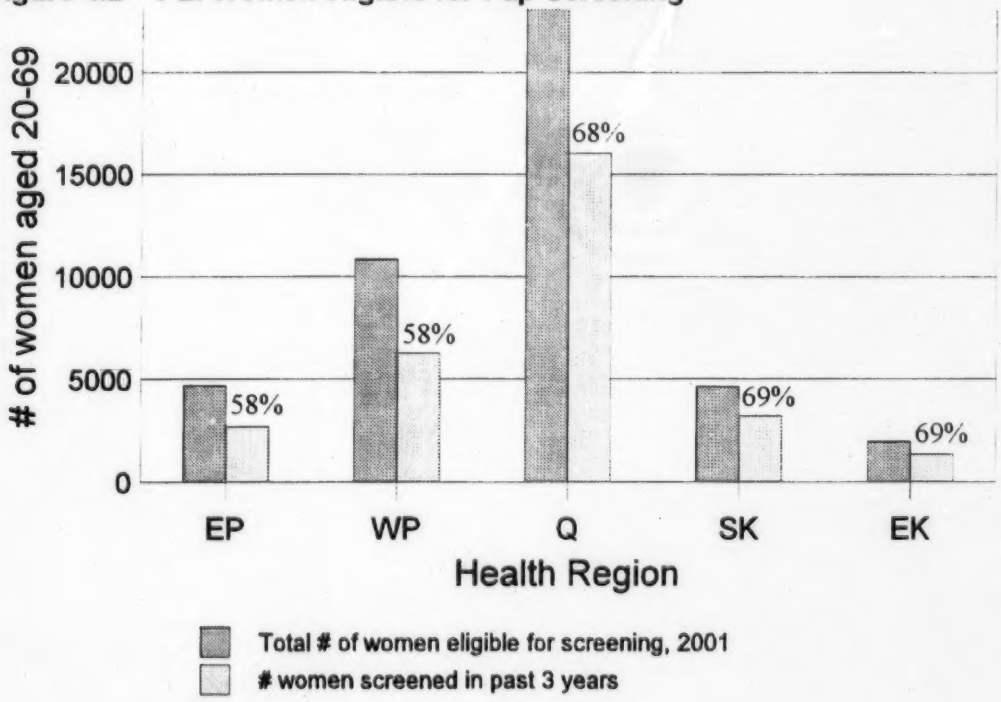

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High Grade Changes[3]	9	4	3	5

[1] includes changes within normal limits and benign cellular changes
[2] includes LSIL, ASCUS, and AGUS non-suspicious
[3] includes HSIL, AGUS suspicious for malignancy, and carcinoma

[7] 2000 CytoBase Report. Insctye Corp. 2001.

4.4 Follow-up Recommendations

The laboratory report to the physician for each smear includes both the results and a recommended interval for follow-up. The follow-up may involve another pap test, or other investigations such as colposcopy, biopsy, or clinical treatment. Recommendations are based primarily on the current cytology result, but may also be influenced by the patient's clinical condition and Pap test history. Table 4.5 presents details of recommendations by cytology result.

Table 4.5 PEI Follow-up Recommendations, 2001

Cytology Result	Follow-up Recommendation (# of Pap tests)			
	3 to 6 months	12 months	1.5 years	no recommendation
Normal[1]	102	19,863	1,101	1,166
Low Grade Changes[2]	470	85	11	4
High Grade Changes[3]	120	0	0	2
Unsatisfactory	29	13	2	4

[1] includes changes within normal limits and benign cellular changes
[2] includes LSIL, ASCUS, and AGUS non-suspicious
[3] includes HSIL, AGUS suspicious for malignancy, and carcinoma

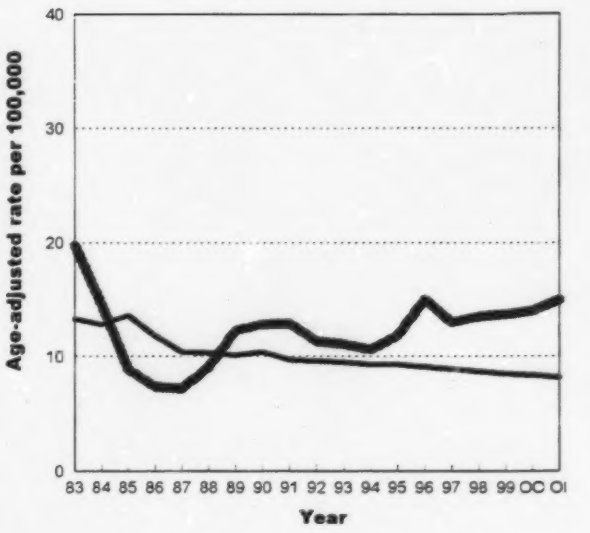
Overall, the laboratory reports provided recommendations for 95% of the Pap tests. As expected, the majority of Pap tests with results of low or high grade changes had a recommended follow-up within 6 months. The majority of Pap tests with normal results had a recommended follow-up interval of 12 months; this laboratory practice should be reviewed after the PEI Pap Screening Program adopts official screening guidelines.

4.5 Incidence of Cervical Cancer

In Canada, the incidence of new cases of cervical cancer has been declining. In PEI, however, the rate has been increasing, as shown in the figure to the right. The most current estimate of the incidence rate is 13 new cases per 100,000 PEI women, compared to 8 in Canada[8]. PEI has consistently had one of the highest rates of cervical cancer in Canada.

Reduction of PEI's incidence rate of cervical cancer is a long-term goal of the program. However, in the next five years, PEI can expect the rate to continue to increase as screening finds new cases.

Trends in Incidence - Female
Cervical Cancer

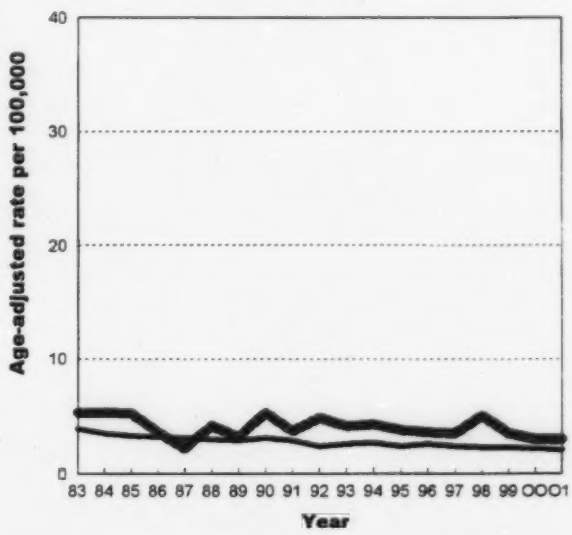


4.6 Mortality of Cervical Cancer

In Canada and PEI, the mortality rate for cervical cancer has been stable, as shown in the figure to the right. The most current estimate of the mortality rates are 3 deaths per 100,000 PEI women, compared to 2 in Canada[8].

The PEI program expects to maintain the stable mortality rate, even as incidence increases, by ensuring follow-up. The long-term goal of the program is to reduce these preventable deaths.

Trends in Mortality - Female
Cervical Cancer



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8 Canadian Cancer Statistics, Canadian Cancer Society & Health Canada, 2002

5. PROGRAM ACTIVITIES IN 2001

The activities of the PEI Pap Screening Program in 2001 were carried out by the Program's Working Groups (see section 3), and were coordinated by the Pap Screening Advisory Committee.

5.1 Pap Awareness Week

PEI's second Pap Awareness Week campaign was held October 20 to 27, 2001. This campaign was the result of a marketing strategy, coordination with campaigns in Nova Scotia and Newfoundland, and evaluation of PEI's 2000 campaign (see Appendix F). The main focus of this campaign was a media blitz and promotional materials with the key messages of:

- cervical cancer can be prevented
- a pap test every two years can save your life
- call your doctor or the Pap Screening Clinic for an appointment

Table 5.1 describes the campaign materials. The 2001 campaign maintained the visual identity of PEI's 2000 campaign.

Table 5.1 PEI Campaign Materials, 2001

Material	Description	Distribution
TV Commercial	three generations of women on the TC trail (produced in 2000)	50 Prime Time airings on CBC for Oct 23 - Nov 6; repeated for 2 weeks in January 2002
Radio Commercial	3 scripts with young, middle aged, and older women	21 ads per week on CFCY, CHTN, Magic 93, C102 for October 22 - Nov 12; repeated for 3 weeks in January 2002
Brochure	"You can prevent cervical cancer" (updated in 2001)	16,000 to 80 physician offices, 44 pharmacies, 30 health organizations
Poster	"You can prevent cervical cancer"	600 to physician offices, pharmacies, health organizations, 8 malls, 41 grocery stores
Pocket Calendars	"You can prevent cervical cancer"	15,000 to malls, grocery stores, 210 hairdressers, 11 fitness centres, large employers, 70 school staff rooms, 20 libraries

Other activities included notices in church bulletins, and a press release (shortly after the Minister's press conference for the opening of the Pap Clinic).

5.2 Cytology Laboratory

PEI has one centralized laboratory for the interpretation of smears located at the Queen Elizabeth Hospital. Pathologists also provide histology results at this hospital, and the Prince County Hospital.

Cytology and histology results in PEI were computerized using the Laboratory Case Management System (LCMS), developed in 1996. The LCMS produces:

- case reports for each cytology and histology specimen
- annual summaries of Pap test adequacy for each physician
- laboratory summary of correlation between cytology and histology reports
- data for the Pap Screening Program's performance indicators (see Appendix I).

Upgrades to the system are underway to allow for additional summary reports to physicians, and notification letters to women (see Appendix J).

Turn around time for cervical smears is measured as difference between date the smear was collected, and date the laboratory report was finalized. This time does not account for the time required for the report to travel from the laboratory to the doctor's office, or the time required for the doctor's office to contact and discuss the results with the woman. Table 5.2 describes PEI's turn around time over several years. In 2001, the average turn around time was 10 days. This is similar to the 14 days reported in Nova Scotia[5], and well within the nationally suggested time of one month[1] that was reported in British Columbia[6].

Table 5.2 Cytology Turn Around Time, by year

	Year				
Turn Around Time	1997	1998	1999	2000	2001
Mean # of days	25 d	6 d	12 d	13 d	10 d

5.3 Screening Guidelines

Screening guidelines for the PEI Pap Screening Program are under development. The major resources for this are:

- 1989 National Workshop on Screening for Cancer of the Cervix[9]
- International research that suggests screening every three years within an organized program results in about the same reduction in cervical cancer as does annual screening[10]
- Programmatic Guidelines for Screening for Cancer of the Cervix in Canada[1], published by Health Canada in 1998 and endorsed by the Society of Obstetricians and Gynaecologists of Canada, the College of Family Physicians of Canada, the Society of Canadian Colposcopists, the Canadian Society of Cytology, and the Society of Gynecologic Oncologists of Canada.
- Statement (in 2000) of the PEI Medical Society's Health Promotion Committee:

  "By the time you reach 18, you should start having Pap tests. The test should be repeated at least **every two years** until age 70."

Once the program guidelines are drafted, consultations will take place with gynecologists, the PEI Medical Society, and other interested groups. Consultations will be overseen by the Advisory Committee.

5.4 Performance Indicators

Performance indicators provide measures of program effectiveness and efficiency, providing the program with information for program management and accountability. The DHSS Epidemiology Unit used data from the laboratory's information system (see Appendix I). The indicators produced are found in Section 4 of this report. As well, the Epidemiology Unit has contributed toward "Cervical Cancer Screening in Canada: 1998 Surveillance Report", scheduled for release by Health Canada in 2002. Other indicators will be added as data is available and the methods are developed.

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9 Miller, Anderson et al; Canadian Medical Assoc J, 1991

10 IARC Working Group on Evaluation of Cervical Cancer Programs. (1986) Screening for squamous cervical cancer: duration of low risk after negative results of cervical cytology and its implications for screening policies BMJ 293:659-664.

5.5 Pap Screening Clinic

A model Pap Screening Clinic was launched September 6, 2001 in Cornwall, PEI. The goal of the clinic is to increase the number of women regularly screened with a Pap test, by providing an alternative service to increase accessibility. Specifically, the clinic expected to provide Pap tests to women with at least a 2 year interval since their previous Pap test (1500 women in year one or 50% capacity, and 3000 women in year two or 75% capacity).

Services provided at the clinic include:

- Toll free number to book appointments: 1-866-818-7277(PAPS)
- Pap test by a trained Registered Nurse
- Resource material for pap and breast screening programs
- Pelvic exam by Dr. D.I. Stewart (if woman is at risk of ovarian cancer)
- Letter with results mailed to women
- Copy of results to the family physician
- Contact with family physician to ensure follow-up
- Follow-up provided by Dr. D.I. Stewart (if woman is without a family physician)

Breast exams were not included, since they are not suitable for routine screening[11]. The clinic does not replace a physical exam, or other related services (such as birth control or hormone replacement therapy) that still require a visit to the family doctor.

Evaluation of the Pap Screening Clinic is done by the Epidemiology Unit, DHSS for the PEI Pap Screening Program. Final results will be available in 2003, providing recommendations for future clinics.

Preliminary evaluation was completed, using the 4 month period September to December 2001 (details in Appendix K). Overall, the clinic was working successfully, with women attending the clinic providing high general satisfaction ratings. The evaluation also provided a description of the women attending the clinic:

- 477 women had a pap test (56% of capacity)
- 75% of women had their last Pap test two or more years ago (42% had last Pap 5 or more years ago)
- 86% of women rated having the Pap test as "very good"
- 7% of women needed to see Dr. D.I. Stewart
- 10 women required follow-up; 6 were referred back to their family doctor
- 90% of women were pleased to get a letter with results
- 21% of women had a hysterectomy
- 53% of women traveled to Cornwall from outside the Queen's Health Region
- 43% of women made the appointment because

"it had been a long time, I needed to have it done"

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11 Canadian Guide to Clinical Preventive Care, CMA & Health Canada 1994

6. FUTURE CHALLENGES

The PEI Pap Screening Program will continue to work toward becoming an organized screening program. This will require development of activities that have been identified by the Working Groups:

Education and Recruitment:

- increase public awareness and knowledge of the need for regular screening as a preventative health care measure
- disseminate educational resources
- improve access for women with disabilities
- investigate possible collaborations with Breast Health Program
- collaborate with each of PEI's health regions and other health community initiatives to increase awareness, provide resources, and increase recruitment
- increase awareness of the program among health professionals

Performance Indicators:

- establish a set of performance indicators on coverage, screening, quality assurance and management of Pap test results

Screening Guidelines:

- develop provincial screening guidelines clarifying which women need screening and how often Pap tests should be done
- develop provincial notification guidelines for follow-up

Cytology Registry:

- incorporate the approved PEI Screening Guidelines in the cytology registry
- ensure computerized system can provide a list to physicians of patients with abnormal tests, and can provide letters to women with abnormal tests.
- ensure computerized system can provide a list to physicians of women overdue for screening, and can provide letters to these women.

The Pap Screening Advisory Committee recognizes that awareness alone will not increase regular screening rates. One initiative undertaken in the first year to increase access was the Pap Screening Clinic. The Advisory Committee will continue to monitor and evaluate the Clinic to determine its potential to increase regular screening rates. The coming year will include recommendations on the Pap Screening Clinic, and other initiatives to increase regular Pap screening of PEI women.

7. APPENDICES

Appendix A:	**Recruitment Strategies**
Appendix B:	**Liability for Follow-up**
Appendix C:	**Profile of Unscreened Women**
Appendix D:	**Well Woman Clinics**
Appendix E:	**Understanding the Barriers to Pap Screening**
Appendix F:	**2000 PEI Pap Awareness Campaign**
Appendix G:	**Terms of Reference**
Appendix H:	**Detailed Data for Program Indicators**
Appendix I:	**Minimum Data for Screening Registry**
Appendix J:	**LCMS Upgrades**
Appendix K:	**Pap Screening Clinic**

Appendix A: Recruitment Strategies

Recruitment is an important component of a screening program. The Canadian Cervical Cancer Prevention Network produced "Literature review of strategies to recruit women to cervical screening"[12]. The summary shown below is an aid to cervical cancer screening programs that want to increase screening using effective recruitment strategies, while avoiding strategies that are known to be ineffective. Some of the strategies have been used in the PEI Pap Awareness Campaign and in the Pap Screening Clinic. Other strategies listed below will need to be incorporated into the Program in the future, to enhance recruitment of underscreened women.

Recruitment Strategies for Pap Screening

Effective Strategies:
- personal letter from an organized program (most effective when appointment included), with media campaign
- a letter of invitation from a woman's physician, with follow-up phone call
- offering Pap during visit to physician
- offering Pap to hospital inpatients
- women's health clinics with community nurses and education

Potentially effective strategies:
- mobile clinics with education campaign (Thai ♀)
- door-to-door canvassing (African-American ♀)
- financial incentives to physicians (UK)
- small monetary reward to women (US ♀)

Not effective strategies:
- television/other media campaigns (alone, with professional education, with posters/presentations/workshops)
- educational pamphlets (mailed, distributed in hospital, distributed in physician's offices)
- tagging medical records as a reminder to physicians
- letters from organized programs to physicians, requesting their assistance in encouraging screening
- letters to attend a local women's health clinic

Source: Literature Review of Strategies. CCPN, 1996

12 Clarke EA, Majpruz V. Ontario Cancer Treatment and Research Foundation, 1996

Appendix B: Liability for Follow-up

Benson Myles

BARRISTERS
SOLICITORS
NOTARIES

Francis P. Fowler, Q.C.
David G. L. Buffett
Jeffrey P. Benson
R. Wayne Myles
Joan F. Myles
Ann E. McLoughlan, M.Sc. *
D. Mark Pike, A Master of the Supreme Court
Augustine F. Bruce
Lisa A. Byrne
Gary F. Peddle, M.B.A.
Christopher D.G. Pike, FIIC
Keith S. Morgan
Paul D. Linegar *
Geoffrey L. Spencer
Benjamin J. Kavanagh
Karen A. Hurley
*on leave

Articled Students

Jason L.W. Walsh
Jason A. Edwards
Colette M. Goodyear

Suite 900 Atlantic Place
Water Street, P.O. Box 1538
St. John's, Newfoundland
Canada A1C 5N8

Telephone: (709) 579-2081
Telecopier: (709) 739-8184

CASE NOTE

LOST CYTOLOGY REPORT RESULTS IN TRAGEDY AND DOCTOR'S LIABILITY

Braun Estate v. Vaughan (1997), M.J. No. 616

A decision by the Manitoba Court of Queen's Bench has recently come to our attention. We feel that a brief summary of the case would be of interest to our clients in the health care field, and their insurers.

The defendant gynaecologist, an employee of the Thompson General Hospital had taken a pap smear from a patient awaiting a tubal ligation. The resulting cytology report indicated severe dysplasia and recommended that a colposcopy be performed. This report was mailed back to the Doctor. Unfortunately for the patient, the pap smear was misplaced, and the tubal ligation was carried out. No follow up was conducted on the cytology report. The patient, Mrs. Nora Braun, a young married mother of three, continued to experience pain and discomfort . In April of 1993, almost one year after the initial pap smear, Mrs. Braun underwent a cervical biopsy that revealed "an invasive, poorly differentiated squamous cell carcinoma of the cervix". Mrs. Braun was given only a statistical chance of survival. She died of cervical cancer in November of 1994. The missing pap smear result was later located in the Doctor's files. At trial, expert testimony revealed that had the abnormal results of the pap smear been expeditiously acted upon by Dr. Vaughan, Mrs. Braun would have had an almost 100% chance of being cured.

The standard of care addressed by the case dealt not with Dr. Vaughan's medical ability, but rather, with his inability to monitor misplaced reports. While the Court found that the Hospital's clinic had no system in place to monitor abnormal test results, it found that the monitoring of test results was a medical concern, not an administrative one. Therefore the responsibility should have fallen squarely upon the shoulders of Dr. Vaughan, and not those of the Hospital. By not maintaining such a system himself, and by not inquiring whether the Hospital maintained such a system, Dr. Vaughan acted negligently. Dr. Vaughan owed a duty of care to Mrs. Braun, and by not monitoring the test results, he breached this duty. The Court compared the Doctor's actions " to that of an ostrich sticking its head in the sand".

The Court held that a hospital is entitled to expect that a properly trained and competent gynaecologist will know that a cytology report requires follow up. They are also entitled to rely on a doctor to properly maintain his records and fulfil his responsibilities to his patients.

Medical Post, April 4, 2000 "Hospital liable for failing to co-ordinate medical records"
Medical Post, June 6, 2000 "Assuming lab will return results costs MD"

- A routine test showed a precancerous condition - fully treatable since found early. With no follow-up, the patient never learned this until it was too late.
- It doesn't matter whether the doctor is a private physician with hospital priviledges or a salaries employee, hospitals must see to it that there are "adequate procedures in place so that the recipient of test results is dealt with cohesively between the clinic and the lab", said the Chief Justice.

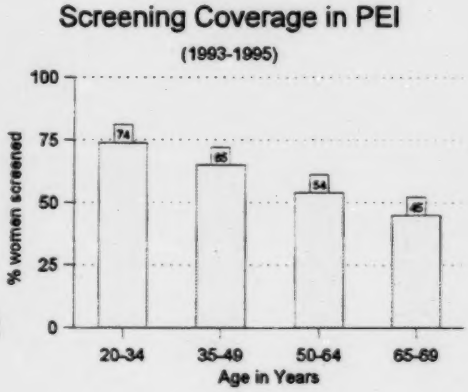
Appendix C: Profile of Unscreened Women

Profile was initiated by a partnership of the PEI Division of the Canadian Cancer Society, and the DHSS Epidemiology Unit, as a basis for development of recruitment strategies appropriate for PEI. The profile was completed in 1997, with funding from Health Canada's Population Health Fund.

Two major sources of information were used; the laboratory cytology data (see Appendix I) for the period 1993 to 1995, and the 1994/95 National Population Health Survey[13]. The two sources were linked together using a unique personal identifier, resulting in a database with 334 PEI women aged 20 to 69.

Screening rates for period 1993 to 1995:

- average annual screening rate was 40%
- three-year screening rate was 63%
- three-year screening rates by health region:
  - EP 48%
  - WP 54%
  - Q 65%
  - SK 62%
  - EK 59%
- screening rates by age are shown on the right
- screening rate for women aged 50+ was not adjusted for hysterectomies



Characteristics of women with no Pap in past 3 years:

- ♀ just as likely to be urban or rural
- ♀ more likely to be aged 50+
  ♀ less likely to be of child-bearing age
- 28% ♀ are smokers (similar to screened women)
- 50% ♀ incorrectly recall their last Pap as within the past 3 years
- 85% ♀ visited a doctor in the past year (similar to screened women)
- 12% ♀ were hospitalized in the past year (similar to screened women)
- 35% ♀ 50 to 69 reported a mammogram in the past 2 years (compared to 65% of screened women)

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13 NPHS Statistics Canada. (accessed on line April 10, 2002 2001) http://www.statcan.ca/english/IPS/Data/82-567-XPB.htm

Appendix D: Well Woman Clinics

In April and May 1998, a series of Well Woman Clinics were organized by a coalition interested in promoting women's health. They organized seven clinics across PEI. The clinics were advertised as available to the public, and asked women to call ahead and book an appointment. All sites provided information on a variety of health topics, sessions on breast self-examination, and Pap testing.

	Souris	Ch'town	S'side	Kens'ton	O'Leary	Alberton	Wellington
health info available	✔	✔	✔	✔	✔	✔	✔
breast self-examination sessions	✔	✔	✔	✔	✔	✔	✔
physician provided pap tests and pelvic exams	✔	✔	✔	✔	✔	✔	✔
physician provided breast exams	✔		✔	✔	✔	✔	✔
blood pressure & cholesterol tests available	✔	✔					✔
Milk Maritime osteoporosis info		✔	✔		✔		
nutritionist available	✔						✔
other services	✔	✔					✔

Results of Clinics:

- 214 women attended the clinics.
- The age distribution of women attending was:
  - 11% aged 20 to 34 years
  - 37% aged 35 to 49 years
  - 38% aged 50 to 69 years
  - 14% aged 70 or older
- 150 women had a Pap test
- 40% of women had last Pap 3 or more years ago
- cytology results of all Pap tests were normal

Family Physician Support:

- described using a mail questionnaire in October 1998, with 38% response
- 64% willing to give qualified support, 36% not supportive
- regardless of the level of support, physicians expressed concerns: continuity of care, duplication of services, heavy physician workload, providing results to family doctors, and establishing eligibility criteria for clinic services
- *"Women were given the incorrect impression that a complete physical examination was provided"*

Appendix E: Understanding the Barriers to Pap Screening

Understanding the Barriers to Cervical Cancer Screening in Prince Edward Island

Dr. L. Van Til, Dr. C. MacQuarrie, Rosemary Herbert

Abstract

Prince Edward Island (PEI) has one of the highest rates of cervical cancer in Canada. Despite the fact that 90% of cervical cancers can be prevented by regular pap screening, 32% of women in PEI aged 45 to 70 had not been screened over a five-year period (1995-2000). To better understand the barriers to screening experienced by these women, sixty unscreened women were randomly selected to participate in five focus groups held during April 2000. Discussions were transcribed and analyzed for themes using an inductive approach. Emergent themes were contextualized within a population health model to guide interpretation of the findings. The main finding from this research is that women who have avoided a pap test are falling between the cracks created by a complex interaction between personal experiences and the health system's approach to pap screening. For example, a common barrier for women was feeling healthy within a system that emphasizes physician visits for illness. This allowed women to procrastinate on getting a pap test, especially with a lack of communication with their physician and lack of reinforcement about the importance of pap screening. This qualitative research contributes to understanding how health systems interact with individual experiences within a population health model.

Prince Edward Island (PEI) has one of the highest rates of cervical cancer in Canada[1]. The PEI annual incidence of cervical cancer is 12 per 100,000 women, and the PEI annual mortality rate for cervical cancer is 5 deaths per 100,000[2] .

Cervical cancer is slow to develop. The cells of the cervix go through mild to severe changes over a period of years before the cells change to cancer. This means over 90% of cervical cancer can be prevented by regular pap screening[3]. Despite this, about 40% of PEI women eligible for screening (age 20 to 69) are not screened regularly[4].

In PEI, the majority of cervical cancer cases are in women who either are not screened or are screened inadequately with a pap test[5]. National guidelines for prevention of cervical cancer recommend regular screening every three years[6]. Among PEI women aged 55 to 69, 50% are screened regularly, compared to 74% of women aged 20 to 34, and 65% of women aged 35 to 49[4]. PEI women currently have opportunistic access to screening through family physicians. This means the pap test is left to the discretion of the woman and her physician.

Previous research[7] provides a long list of potential barriers to pap screening. However, previous studies could not differentiate between regular and infrequently screened women. To better understand barriers to pap screening, research must focus on women who do not regularly have a pap test. Furthermore, the literature contains neither a clear explanation of what the list of barriers to pap screening mean for women, nor how these barriers interact[7].

Understanding of health and illness behaviour is incomplete unless an attempt is made to capture the subjective reality from the individual's perspective[8]. This is best accomplished through the use of formative research methods, including focus groups[8,9]. Focus groups are valuable in gaining rich detailed perspectives through sharing and comparing of responses among participants[10]. It is a useful methodology when insights are needed in exploratory or preliminary studies or when the purpose of the research is to uncover factors relating to complex behaviour or motivation[11]. This study utilized focus group methodology to garner women's accounts of their experiences with pap screening.

Interpretation of focus group results was guided by the Population Health Promotion Model[12]. Effective health promotion is depicted as a tripartite interaction among three dimensions: strategies, populations, and determinants of health. The first dimension, strategies, encompasses how population health can be improved, while the dimension of population describes the levels of interaction ranging from individuals within families, to communities, through to various sectors within society. Determinants of health include aspects of culture, gender, income, social status, social support networks, access to health services, education, employment and working conditions, early

childhood development, and personal health practices and skills. Thus the model provides a framework for understanding how individuals interact with health systems in a way that can make sense of some of the barriers encountered by particular populations.

In PEI, women not screened regularly for cervical cancer are likely to be older, just as likely to be rural or urban, and the majority (85%) have seen a doctor in the past year[4]. Research findings consistently identify older women as underscreened[13,14], indicating a paucity of information on how to improve this statistic[15]. The objective of this study was to better understand the barriers to cervical cancer screening and their interaction from the perspective of older women on PEI.

Method

Focus group methodology was utilized by this study, and approved by ethics review boards at the University of PEI and Queen's Region Health.

A series of five focus groups were held across the province, with one conducted in each of the province's health regions. The use of small regions was designed to increase the comfort level of participants with sharing experiences in a focus group[10]. Eligibility criteria for inclusion in this study were: (a) women between the ages of 45 and 70; (b) who had not had a pap test in the previous five years; and (c) had an intact cervix.

The eligibility of women was determined by the PEI Department of Health's Epidemiology Unit, using linkage of the laboratory cytology database and the population registry. A random sample of 213 women (stratified by health region) were telephoned by the Epidemiology Unit and confirmed as eligible for the study. Women who agreed to participate were sent a letter of confirmation and received a reminder telephone call the day before the meeting. All participants received a $50 travel honorarium. The five focus groups were held during May 2000.

Focus groups were held in the evening from 7:00 until 9:00. Upon arrival, all participants were asked to sign consent forms. Women were greeted at the focus groups by the researchers who made the telephone calls of invitation and who were the moderators for the session. This was done strategically to set women at ease and to enhance rapport for the discussions. Establishing rapport with participants was essential for success of the focus groups, as the topic was a highly personal one, and few group members knew one another prior to the focus group. Therefore the trained moderator needed to create opportunities for establishing trust and communication amongst women to enhance sharing of personal information in a relatively short time[16]. The moderator also kept the discussion on track, involved all participants, and probed certain questions in order to gain greater insights into barriers. The moderator used a semi-structured interview script[17] to ensure three key questions were addressed: (1)What is your experience with having pap tests? (2)When you consider all of the reasons, what is your main reason for not having regular pap tests? (3)What would make it easier for you to have a pap test every two years?

Focus group discussions were audio taped and later transcribed verbatim with all names removed. One researcher was primarily responsible for moderating the session while the other took field notes of salient points of discussion, observed the group dynamics, and tended to the logistics of equipment set up and monitoring.

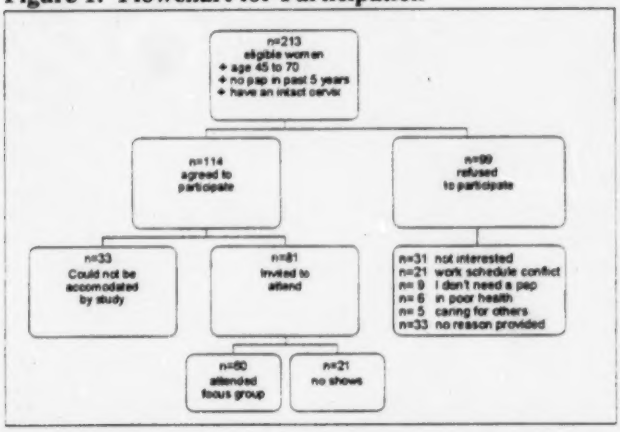
Analysis

The analyses were conducted by researchers who had not conducted the focus groups, using the transcripts (10 hours of transcribed tape) and copies of the field notes. Thematic analysis was used to identify recurring themes in the data. The transcripts for the five focus groups were read by two researchers who independently assigned codes to identify distinct themes[18-20]. The two researchers met to discuss the codes and to develop an overall categorization, following an inductive approach for the structure of the interpretation[21-23]. The transcripts were reread following this emergent categorization method. Emphasis was placed on examining the transcripts for any sections which did not fit the emergent organization framework[24,25]. Next, the Population Health Promotion model[12] was used to enhance interpretation of the findings. The population dimension provided broad categories of systemic and individual issues for the determinants of health described by the participants. Improvements to health were organized using the strategies dimension, as evidenced in the discussion section of this study. The framework was discussed by the research group, including focus group moderators and an independent reader of the transcripts and field notes. Examination and interpretation of the data from several different perspectives, including written responses to the second key question that did not mention new barriers, provided a measure of trustworthiness. The process of hermeneutics, or interpretation through iteration and returning to the original transcriptions[21], resulted in the consolidation of some categories within the framework, and provided new insights to the interpretation of other categories. This provided a check for comprehensiveness of the interpretation[26] and provided additional validity for the interpretation[27].

Participants

Women unscreened for 5 or more years represented 32% of PEI women aged 45 to 70. Of the 213 eligible women contacted, 113 [53%] agreed to participate (see Fig. 1). The two most common reasons given for refusal to participate were disinterest, or a seasonal work schedule. Once invited, 74% [60/81] of the women attended the focus group.

Figure 1. Flowchart for Participation



All 60 women attending the focus groups had not had a pap in the past five years. This ranged from never, to once 27 years ago, to every five years. All 60 women were between the ages of 46 and 70, and came from varying educational backgrounds.

Women attending the focus groups were representative of women who had not had a pap for at least five years (unscreened women). This was demonstrated by the eligibility criteria, the response rate that was comparable to mail-in surveys[28], the even distribution among age and education levels, and the consistency of the themes appearing across all focus groups.

Results

Across focus groups, themes emerged along three key areas, as shown in Figure 2. These themes of personal experience, system issues, and advice for improvement, were consistently seen in all five focus groups.

Personal Experience

One set of themes centred around personal experiences. Women perceived pap screening along four sub-themes: during the pap, around initiation and follow up, value of self, and their relationship with their doctor.

During the Pap. Women were asked what came to mind when they thought about pap screening. A number of their responses related to the actual experience of having the pap test. Women described a range of experiences. They talked about the position of their bodies, "being exposed", the coldness of the room, the sound and feeling of the paper on the table, and some described pain. Other women indicated, "it doesn't hurt."

> *"No, I tense up too when I go to them. I hate going to them and I won't. Well you get nervous and you just kind of get tense."*

One woman who was in a wheelchair described the lack of dignity she felt in trying to access a pap test:

> *"Because I have to have somebody to help me, it's been 27 years since I've had a pap smear . . . and I've never been back because those tables don't come down so there has to be a man come in to lift me up and no thank you."*

Other women also described feeling a lack of dignity during the pap test. Associated with embarrassment with the test were also expressions of vulnerability through not knowing what to expect:

> *"It's been 23 years since I had a pap test. And I'm too nervous to go . . . It was the only one and I remember it. Well, just there with my feet stuck up in the air." Did you know what the doctor was doing? "Well no, the sheet was up and you couldn't really see him. But I could feel him probing around. But it was embarrassing. And I never went back."*

One woman disclosed being "sexually assaulted" by her physician during the pap test. During focus group discussions, some women described feeling as if they were "molested" during their examination. Another woman described having flashbacks to being molested as a child:

> *"I can go back and I can relate to being molested as a child, now whether that has anything to do with it or I am using it for an excuse, but I feel that I have ... when they're going all over me and . . . the feeling comes back."*

Thus women's stories of pap screening ranged along a continuum of experiences from mildly unpleasant to intensely traumatic. No women shared examples of pleasant experiences. The most positive comments were of the sort that the test itself wasn't any big deal. The most common feeling was one of discomfort and embarrassment.

Initiation and Follow-Up. Women's experiences also related to how they thought about the pap and they expressed a range of feelings surrounding the initiation and follow-up of the pap test. When asked why women don't take responsibility to request a pap from their doctor, a common response among women who had close family experiences with cancer centred around fear of the result:

> *"I think fear is a lot of, they've made cancer such a fearful word . . . I'm an ostrich. I stick my head in the sand, and if there is a problem I don't want to know."*

"I have a sister that did have cervical cancer ten years ago . . . she goes every year for her pap smear but she's been fine. She's strong, very strong. She's different than I am. I'm not strong you know . . . I did too until I got older. I live alone so why is it necessary? . . . Ignorance is bliss."

Some women indicated that just asking for the test was a major barrier. Some women found it embarrassing, "asking for the test." For some women the fear of the results meant they needed to work up the courage to even ask for the test, " . . . so why think about it, something you can avoid." Some women described needing "to get myself in a mind-set to go" before they could request the test. Women also indicated their avoidance of an uncomfortable experience was part of their reluctance to make an appointment:

"Yeah, you can start feeling the heat, and the sweats, just start sweating. I've only had one in all my years. . . . just the thoughts of it."

"I just don't like it because I feel like I just don't want to go there and undress in front of a male."

Thus the potential of the test to give negative news and their personal experiences of the tests as women being examined by male physicians contributed to women's resistance to request a pap test.

Value of Self. Women expressed a variety of issues in relation to valuing of self. Some women expressed reluctance to disrobe connected to feelings about their changed physical appearance:

"I think that some issue would be that once you're 45 and a little bit older, most of us . . . don't have our 20 year old figure anymore and that's kind of makes it a little embarrassing . . . "

Women understood the pap test to be a recognized test for health maintenance. They spoke of valuing the pap test for their daughters, but not for themselves. Therefore, even though some women were aware of the need for regular pap tests, it was not a health precaution they were actively pursuing for their own health.

"I know I hound my daughters and nag them to make sure that they always go, although I don't, but I am very conscientious that they go and I will hound them until they do. I just keep going on, 'Did you go yet?'"

It seems some daughters must reciprocate and encourage their mothers to have pap tests because of the sentiment expressed by one woman:

"I tell her look after yourself, don't worry about me."

In discussing reasons for not having a regular pap test women across the five focus groups voiced a recurrent issue of time compression and of having no time to look after themselves. Women spoke of putting other's needs ahead of their own as a reason for not having a pap test. This was expressed through quotes such as the following:

"I'm not sick, I'm tired. I have 6 children and a very sick husband and I have been so busy that I just did not go."

"I think we as women should take better care of ourselves; we're going to have to start taking better care of ourselves. We put everybody else first, like I mean we should really be having pap tests and stuff, we should be doing it."

Thus women appeared to value other's needs over their own.

Relationship with Doctor. Another thematic area within personal experience draws upon women's relationships with their doctors. Women spoke of positive experiences with their gynecologists. In particular, they described the feeling of security and trust they felt in having a specialist with whom they were familiar attend to their needs:

". . . that's what they're trained for and they know every question you might have and they make you feel at ease and you see the same people every time you're back."

Retirement of their gynecologist created problems of confidence for these women:

"I always had them done with my gynecologist while I was having my children and up until he retired. Now I feel uncomfortable to have my family physician perform this test. The pap screening itself was never a problem."

Some women stated they'd prefer to not have a local doctor for their pap test:

"And it's really hard to sort of step back and let him be the doctor rather than the neighbour or the friend."

Some women perceived their doctor's approach as too cavalier:

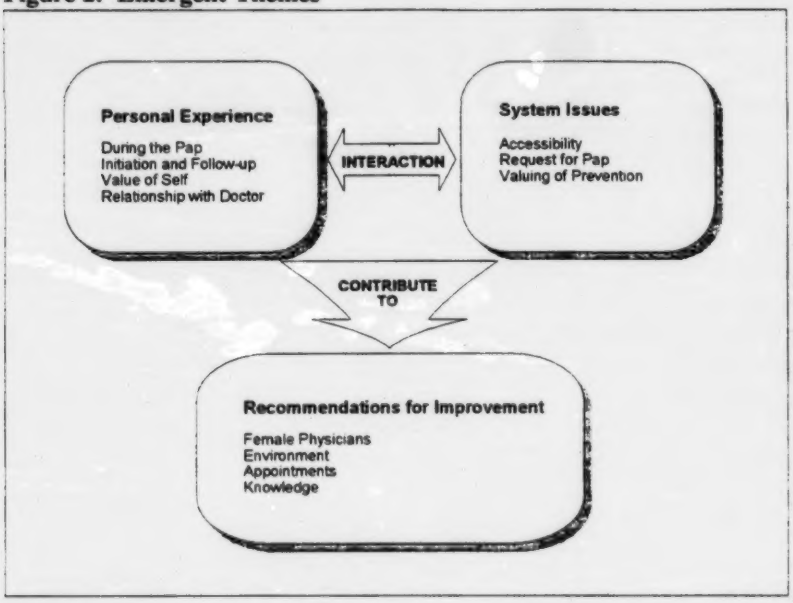
"the fact that it's so routine and to us as an individual it's not routine, it's an invasion of your body and there's a certain sensitivity that needs to be there when this is being done . . . like it's a routine thing to a doctor but to us it's very traumatic."

Women also expressed the desire to have a woman perform the pap test instead of a man. Women physicians were perceived to be more understanding:

". . . a woman doctor would have more understanding of what you go through when you have yeast infection. Therefore a woman doctor, you think, is going to be more compassionate, more understanding."

"It's not just that, it's also the fact a female is more sensitive to the problems you may have. You mention them to your male doctor and he says 'Uh Uh' and goes on to something else."

Figure 2. Emergent Themes



Women indicated a range of experiences with their physicians ranging from positive to negative. Some women felt if they could communicate with their physicians to establish professional trust, then they could overcome their embarrassment and discomfort with getting a pap test. These women had a yearly commitment to pap screening that ended when their gynecologist retired. Other women who had not had this relationship with their doctor described their preference for a woman to perform the test, or for their doctor to have a communicative bedside manner. Thus, a woman's relationship with her doctor was an important consideration which could facilitate or hinder her access to pap screening.

System Issues

The second key theme area was related to the health care system . These issues were clustered around three sub-themes: accessibility, how the pap test is requested, and the value attributed to pap screening.

Accessibility. Accessibility was a frequently occurring theme that included accessibility to physicians and issues regarding time involved with pap screening. Women found that access to physicians had been altered or decreased through retirement of physicians, inability to find a replacement physician with whom women felt trust and were comfortable, and the fact that many doctors were overextended and not taking on new patients. Several women stated they did not have a doctor. Some women indicated they felt more comfortable going to a specialist but that it was now very difficult or impossible to access specialists:

> *"We went to the specialists and therefore that became a little bit more comfort because you were going to a specialist over an annual women's check up and a pap test and a lot of those things. But now you don't go to a specialist for those things, you leave it up to your GP."*

Time was a common theme expressed in a variety of ways. Some women felt doctors generally did not have the time to answer questions or to do pap screening in a non-hurried, relaxed manner. Others indicated that physicians' hours were problematic for some working women. In some cases women found it difficult to get time off work for health care and therefore would not go to the doctor unless it was absolutely necessary. Many women waited two to three months for an appointment for a pap test. Several women expressed that once they decided to have a pap test, they did not want to wait several months:

> *". . . if I'm ready to go I want to go and have it today or next week, I don't want to be put off . . .We shouldn't have to wait six months."*

Women were also frequently kept waiting during the actual appointment time. Many women described the process of waiting as worrisome and tedious:

> *". . . I waited nearly an hour in the outer office . . . I'm laying on the table probably fifteen minutes but it seemed like an hour."*
>
> *"You're sitting there with this little thing across you hoping nobody else is going to come in. . . . And then you sit there and sit there and sit there and wait and wait and wait and you wonder."*

Request for Pap. A second sub-theme centred around women feeling they have to request pap screening and that this responsibility was left to them. Women indicated that pap screening was not usually offered even to those women who visit their physician regularly for other health issues. Some women found it difficult to request a pap test and would prefer the physician initiate this suggestion. Other women indicated if the doctor did not suggest it, they were not going to initiate the discussion:

> *". . . it's just getting nerved up to make that appointment. It doesn't seem as scary when it comes from the doctor than it does if you have to do it yourself."*
>
> *"She treats me for high blood pressure . . . (I visit) 3 times in 6 or 8 months. But there's nothing, no reference to pap tests, that's for sure."*

Valuing of Prevention. Many women expressed opinions that reflected their own valuing and their perception of physicians' valuing for pap screening. In general, there seemed to be a lack of valuing of preventive care such as pap screening, demonstrated by their willingness to procrastinate if they felt fine. Some women indicated the only time they sought health care was if they were sick or had a problem:

"I don't think I need one. I have no feeling that there is something wrong you know. I'd have to have that feeling that I have something wrong here, something went wrong you know, that way."

"If you're not sick you don't go . . . It's not broke, you're not going to fix it."

The issue of women as caregivers arose in that women are frequently caring for dependents such as children. While they seek out care for their children, they are not so effective at obtaining care for themselves:

"When it comes to you doing it for yourself its like Oh God, they're going to think I'm a pest so you have a tendency to let it just slide."

"The kids are always sick, you're always in there, it's like here she comes again."

This theme of valuing extended to discussions around why women engage with the health care system. During the child-bearing years, many women visit physicians regularly for obstetrical care and for birth control. When women do not have a reason to seek out health care, many choose not to visit a physician unless they have a problem:

". . . you see a doctor anyway if you're having children and the like. It's par for the course because . . . you can't get the pill without seeing one, having a doctor do this."

Women look to physicians for cues about the value they attribute to pap screening. Many of the women indicated their physicians did not discuss pap screening. Even when a nurse in a physician's office suggested that a woman have a pap test, she did not follow through with this suggestion since the physician did not mention it. Most women felt doctors should know when women need paps and suggest women have them:

"Well, I haven't had the same doctor, like there's been two or three doctors since. They never brought it up, but then I haven't either."

Recommendations for Improvement

As seen in Figure 2, women's personal experiences interacted with system issues, influencing the third key theme area of suggestions for improved pap screening participation. The improvements were organized by four sub-themes: female physicians, a relaxed environment, pre-arranged appointments, and knowledge of pap screening.

Female Physicians. A repeated sub-theme was having women physicians conduct the procedure. It was felt that going to a woman physician would be less embarrassing and more relaxing. Women physicians were perceived as being more understanding, gentle, and compassionate. Some women indicated they would feel more comfortable going to specially trained nurses:

"The man thing is a big stumbling block. I'd hunt all over this island for a woman doctor if I thought I could get in to her."

Understanding of this recommendation is rooted in women's description of relationships with doctors. Women could overcome negative personal experiences if their relationships with doctors involved enough communication to establish professional trust and understanding. Some women described this relationship along professional lines, others along gender lines. The message of communication was reinforced by the perception that women doctors would be more understanding.

Environment. Women talked about the uncomfortable, clinical type of environment as a deterrent and emphasized the need to provide a pleasant, relaxed environment. Many suggestions were made regarding the waiting area and making the actual procedure more comfortable. A friendly atmosphere with music and warm blankets was suggested. Privacy before and during the procedure was seen as essential. More flexible hours and evening appointments were suggested as ways of increasing the accessibility for working women.

"I just gave up on going because I'm uncomfortable and I'm there shivering and I'm uptight when they're doing it and he's there hollering at me, 'Relax! Relax!' Well I can't relax and it's cold and it's hard."

"where several women could come in together . . . mothers sitting with daughters, or sisters, or best friends came in together and they were able to reassure each other while they were waiting and they had snack there for them and information was available."

A variety of settings for pap screening were also suggested, such as drop-in clinics, travelling clinics, and clinics staffed by public health nurses. Some women had heard the 1998 pilot Well Women Clinics were a positive experience. Many women liked the concept of attending a clinic that conducted both mammography and pap tests:

"Maybe it would be a good idea to have a clinic at the mammogram. When you have your mammogram you have your pap test at the same time."

Appointments. For many women, the most difficult part of getting a pap test is making the appointment. Pre-arranged appointments were a commonly mentioned

suggestion. Many women felt they would be more likely to attend appointments that were booked for them. If left to make their own appointments, they might never get around to it. Having physicians suggest or initiate regular pap tests was also seen as positive:

"I see the doctor eight times a year . . . I don't like to ask for anything . . . the test. I think the doctor should ask us 'Have you had one or do you want one?'"

"That's how I got my first pap test, my sister-in-law made the appointment for the two of us."

Knowledge. The need for knowledge about pap screening emerged as a strong sub-theme. Some women had incorrect information while others indicated a need for more information. Examples of some of the myths that were shared include:

"I don't have to have a pap because I'm not sexually active anymore."

"You can never get rid of cancer."

"Rather than take the cure, I'd live with the disease."

"I don't have any history of cancer of any sort in my family . . . I don't think I need one."

"I figured that I am old, not old but 65 . . . so I don't need a pap anymore."

Some women felt it would be valuable to receive the results of the test. Women are presently only informed if there is a problem. Women generally knew that they should go for pap screening, but not that it could prevent cervical cancer:

"One thing that bothers me, 'a pap test every 2 years prevents cervical cancer'. I'm sorry I don't think there's anything that can prevent cancer. A pap smear will detect it, but (not prevent it)."

Women also expressed a need for more information about who should be having pap tests, how to prepare for the exam, the benefits of having regular examinations, and basic information about the preventive nature of cervical cancer. In some cases it was stated that if women were better informed about the benefits of pap screening, they would be more motivated to have it done.

"Because they're pushing now more on the TV more on the mammograms and nothing is said about going for pap tests, about an internal for women. That would give us a click to say OK . . . "

Discussion

Unscreened women across the focus groups began their discussions with candid personal accounts of their experiences with pap screening. Women spoke poignantly about their experiences which ranged along a continuum from mildly unpleasant to intensely traumatic. Many expressed feelings of discomfort and embarrassment, as previously described[29], but these women put this in the context of discussions about pain, dignity, and molestation. This experience, combined with fear of results[29], and valuing others needs over their own[30-32] demonstrate that unscreened women construct the test as something to be avoided, and leads to difficulties initiating an appointment for a pap test. Interactions among personal experiences were demonstrated by the pervasive effect of these women's relationship with their doctor. Women felt that a relationship that involved "professional trust," whether with a gynecologist, a non-local doctor, or a female doctor, could overcome their negative personal experiences.

System issues of accessibility described by these unscreened women included inability to access gynecologists, and waiting time. Some previously described American accessibility issues such as cost of screening[33], or lack of health care insurance[34] were not mentioned by these Canadian unscreened women. Unscreened women portrayed a low value for prevention, previously described as "only go to doctor when ill"[35], or lack of knowledge about importance of the pap test[31]. Interactions among systemic issues were demonstrated by the overlap between comments on the lack of personal physician recommendation for a Pap test[30,36], and comments on reasons for visiting the doctor.

The major finding of this study was identification of how unscreened women's experiences interact with various elements of the health care system. Potentiating their pattern of avoidance is the myriad of competing demands experienced by women as well as inadequate communication with doctors to establish professional trust and understanding. Interacting with these constructions are women's perceptions of pap screening as inaccessible and in some cases unimportant. These perceptions were formulated by situations where despite having multiple contacts with the health care system, little or no emphasis was placed on the importance of regular pap screening. Women also described a lack of public education about the preventive value of pap tests. Many women felt that initiating discussion and/or action regarding pap screening was a burden to them personally. Thus unscreened women's generally negative experiences with pap screening and their perceptions of the low priority of pap screening by the system, interacted to produce a low screening rate.

The current balance of responsibility for pap screening needs to be re-negotiated so that women feel more support from physicians and the health care system for preventive health care. There should be room for negotiation between a woman and her physician for the degree of responsibility that will be taken by each. It is not appropriate to assume that every woman will assume the same degree of responsibility for pap screening. Rather the system needs to

be flexible enough to accommodate the level of involvement that each woman seeks in her health care.

There are several ways in which the balance of responsibility between women and the system can be shifted. The first is through a letter of invitation sent to each woman which would provide a reminder and some information about the benefits of pap screening. This strategy would still require the woman to make an appointment and for some women this will suffice. For others, additional notification of their physician is required. Physicians need systematic information about their patients who are overdue for screening, in order to encourage their assistance in recruiting these women.

A second area where the system can show improvement is through the completion of the circle of engagement by actively communicating test results to women. Women are currently functioning within a system where it is assumed that no news is to be interpreted as a normal test result. Women expressed the wish to be informed of their test results. Information sharing is important because it conveys a message that women are important enough to be told of their results. Women told us receiving normal results is like 'getting a compliment'. Strengthening and completing the circle of engagement requires communication between the system and women. This builds trust and respect and ultimately works to increase patient empowerment. Working in a system of not hearing can exacerbate the uncertainty associated with screening. This adds to the negative experience of screening for women who are already anxious about the test.

Once a woman overcomes the barriers to screening, the next part of the solution centers around the environment into which she enters for her pap. A 'friendly' environment would make the experience less intimidating and increase the chances of her returning for future appointments. Women had many suggestions for improving the environment: the provision of refreshments, flexible hours, music, warm surfaces, privacy, and having female nurses and physicians conduct the screening. Also, having a special place where women 'know why everyone is there' will help to counteract the feeling that people should only go to the doctor for illness and help to reinforce the importance of prevention.

Solutions to increase pap screening must be multifaceted to address the complexity and interrelatedness of the issues articulated by women. The recommendations suggested by women in the focus groups underscore the need for a comprehensive strategy. A comprehensive strategy can best be achieved by engagement of women, health care providers, and policy makers. These recommendations fit within many of the strategies outlined in the Health Canada Population Health Promotion framework[12]. The strategies include building healthy public policy, reorienting health services, creating supportive environments, developing personal skills, and strengthening community action. Strategies supported by unscreened women for building healthy public policy and reorienting health services include increasing the value of preventive care such as pap screening, and placing more responsibility on the system for monitoring of regular pap screening. Strategies to create supportive environments for women range from changes in the physical environment to creating opportunities for women to support one another. Strategies to develop personal skills include provision of information in many formats about who should be screened, how to prepare for the test, the benefits of having regular exams, and basic information about the preventability of cervical cancer. Some women were basing decisions on incorrect information such as not needing a pap because of sexual inactivity or because of being over a certain age. Unscreened women felt that accurate information would increase their likelihood of having regular pap screening.

Future research is needed to examine how these recommendations can be implemented, and to document the impact of these changes on the health system and women's participation in pap screening. Specific areas of study might include the shift to different partnerships amongst physicians and other health care providers as women place demands on the system to meet their screening needs.

In conclusion, a complex interaction between a woman's personal experiences and the health system's opportunistic approach to pap screening work to create a high rate of unscreened women in the province. Women's desire to avoid past negative experiences are reinforced by the health system's current approach to pap screening. The interaction creates a systematic gap which contributes to PEI's poor record for pap screening, essentially allowing pap tests to go ignored. Older women in particular are finding the opportunistic screening system failing them as they do not place their preventive health needs assertively in the foreground. A comprehensive set of strategies will need to be employed to deal with the multiple factors contributing to the current low rate of pap screening among older women in this province.

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Appendix F: 2000 Pap Awareness Campaign

PEI's first Pap Awareness Campaign was held October 20 to 27, 2000. The campaign was timed to correspond with campaigns in Nova Scotia and Newfoundland. The campaign followed a social marketing strategy, supported by the partners from the PEI Division of the Canadian Cancer Society, the Medical Society of PEI, and the PEI Department of Health and Social Services. Objectives of the campaign were to:

❶ Increase public awareness of Pap testing

❷ Increase physician awareness of Pap testing

❸ Increase the number of women screened for a Pap test

The main focus of this campaign was a media blitz and promotional materials. All materials provided the key messages of:

- cervical cancer can be prevented
- a pap test every two years can save your life
- call your doctor for an appointment

Table F.1 describes the campaign materials. The 2000 campaign was designed as a recognizable package with all materials using the same actresses and messages.

Table F.1 PEI Campaign Materials, 2000

Material	Description	Distribution
TV Commercial	three generations of women on the TC trail	85 Prime Time airings on CBC for Oct 23 - Nov 19; repeated for 3 weeks in January 2001
Radio Commercial	3 scripts with young, middle aged, and older women	21 ads per week on CFCY, CHTN, Magic 93, C102 for October 23 - Dec 29; repeated for 3 weeks in January 2002
Brochure	20,000 "You can prevent cervical cancer"	80 physician offices, 44 pharmacies, 30 health organizations
Poster	800 "You can prevent cervical cancer"	physician offices, pharmacies, health organizations, 8 malls, 41 grocery stores, 210 hairdressers, 11 fitness centres, 70 school staff rooms, 20 libraries
Pocket Calendars	20,000 "You can prevent cervical cancer"	malls, grocery stores, hairdressers, fitness centres, large employers, school staff rooms, libraries

Other activities included notices in church bulletins, and a feature on "Island Focus" TV program on November 15, 2000. The Medical Society Newsletter contained a description of the campaign and a summary of the barriers research. A press release with the Minister of Health and Social Services on October 20 was followed by newspaper articles and the editorial shown in Figure F.1

Figure F.1 Guardian Editorial, Charlottetown, October 27, 2000

All partners in promoting good health

It's a discouraging statistic that only 40 per cent of Island women are tested annually for cervical cancer.

Health-care professionals and public health advocacy groups are breaking their necks promoting the importance of preventative health, but it appears not everyone is listening. Not if recent statistics on the number of women opting out of annual tests for cervical cancer are any indication.

According to provincial Health Minister Jamie Ballem, only 40 per cent of Island women get a pap test each year. That's in spite of the fact that 90 per cent of cervical cancer can be prevented through the regular use of such tests. That's in spite of the fact that cervical cancer cases in P.E.I. are not decreasing, although they are across Canada.

This is more than surprising. It's dismaying. For years, health advocates - doctors, nurses, fitness gurus, and so on - have been trumpeting the benefits of looking for ways to prevent illness and the deterioration of good health. The shelves of government are sagging with briefs and reports and studies documenting the advantages of healthy lifestyles, preventative health measures and regular checkups. All this to convince governments that it makes good fiscal sense to put money into promoting these measures.

That only 40 per cent of Island women get annual pap tests undermines all this effort. Preventative health care can only be effective if all parties who have a role in it play their part. Lobby groups can argue all they want for government funding to promote it, and government may even concede, but if individuals don't assume personal responsibility for their health, we won't see the improved statistics we all yearn for.

And there are other downsides. We are all consumers of health care. By failing to take advantage of preventative health-care services - such as the annual checkups where women can be tested for cervical cancer - we are suggesting that they're not essential. This is the wrong message to send to governments, all of which need encouragement from the consuming public that preventative health is important to them. We can only convince government that spending in this area makes good sense if we use the available services and, hopefully in time, reap the results in overall improved wellness.

Evaluation of the 2000 campaign was based on the three objectives.

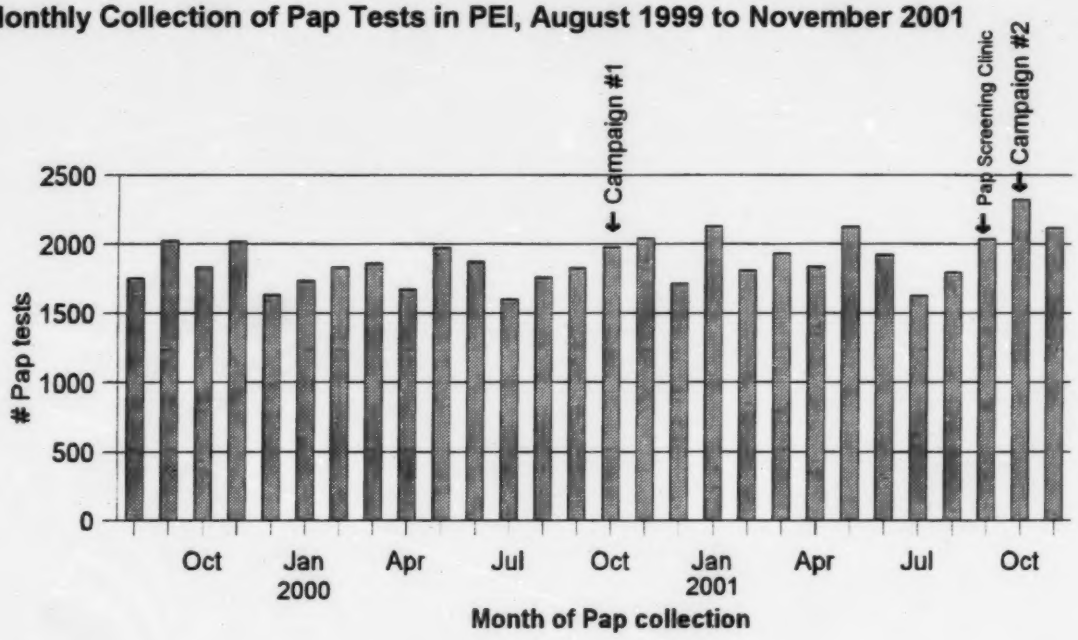
❶ Increase public awareness of Pap testing
- evaluated with a telephone survey of PEI women during February 2001, with 150 respondents (98% participation rate)
- 63% of women aware of radio and TV ads
  (Compares well with 45% awareness for an earlier DHSS campaign on inclusion of persons with a mental handicap)
- 52% of women aware of posters
- 40% of women aware of brochures
- 23% of women aware of pocket calendars
- message recall: women could recall that a pap can prevent cancer; women could not recall that they need a pap test every two years

❷ Increase physician awareness of Pap testing
- evaluated with a distribution survey of businesses/organizations contacted by telephone in February 2001, with 134 respondents (72% participation rate)
- 96% of doctors, pharmacies, stores willing to support future campaigns

❸ Increase the number of women screened for a Pap test

- evaluated using laboratory cytology data (see Appendix I)
- annual PEI screening rate for 1999/00 year prior to campaign: 39%
  annual PEI screening rate for 2000/01 year including the campaign: 42%
  (This slight increase could have been the result of year to year fluctuation in annual screening rates; see Section 6.)
- the laboratory saw a 4% increase in number of smears the year following the campaign, compared to the year before the campaign

Monthly Collection of Pap Tests in PEI, August 1999 to November 2001



Conclusion:

The 2000 campaign raised awareness, as evidenced by the success of 63% awareness of the campaign among PEI women. The impact of the campaign on screening behaviour was of a smaller magnitude. To increase screening rates, the Pap Screening Program will need to look at a more integrated approach of engaging communities, removing barriers, as well as awareness campaigns.

Appendix G: Terms of Reference

PEI PAP SCREENING PROGRAM

***Goal*:** to reduce the incidence and mortality rates of cervical cancer in PEI.

PAP SCREENING ADVISORY COMMITTEE
Terms of Reference

***Purpose*:**

- provide recommendations in the development, implementation, and direction of the PEI Pap Screening Program and provide overall management of the related cervical cancer working groups.

***Membership*:**

- membership will include representatives of PEI Medical Society, Provincial Pathology Laboratory, Women's Network, Canadian Cancer Society, and representatives from PEI Department of Health.

- ***Inaugural members*:**
  Chair: Dr. Linda Van Til, DHSS, Epidemiology Unit
  Teresa Hennebery, DHSS, Division of Public Health and Evaluation
  Johanne Irwin, DHSS, Medical Services & Breast Screening Program
  Dr. Marvin Tesch, Provincial Pathology Laboratory
  Vicki Francis, Canadian Cancer Society, PEI Division
  Dr. Janet Baker, Medical Society of PEI, Family Physician
  Laurie Ann MacCardle, Women's Network
  Heather MacMillan, *Ex-officio*, Program Coordinator

- ***Term:*** 2 year appointment, renewable.

***Reporting Relationship*:**

- the committee will report to the Minister of Health and Social Services, who selects the Chair
- the committee may establish working groups to develop/implement program initiatives,
- budget request and rationale must be submitted to DHSS

***Frequency of Meetings*:**

- the Pap Awareness Working Group will meet at least twice a year. Other meetings, teleconferences and e-mails will occur as necessary.

PAP SCREENING ADVISORY COMMITTEE - T of R cont'd

Roles and Responsibilities:

- Establish the PEI Pap Screening Program
- Develop and encourage the implementation and maintenance of standards of cervical cancer screening
- increase public awareness and knowledge of the need for regular screening (Pap Test) as a preventive health care measure
- increase awareness of the program, its purpose and current approaches, among health professionals
- Insure an educational/awareness campaign occurs
- Recommend cost-effective program initiatives to increase the participation of Island women in cervical cancer screening
- Review national, provincial and regional statistics on an annual basis, and
- Produce an annual report for the Minister

Role of Program Coordinator:

- coordinate activities of Advisory Committee
- support activities of Working Groups
- liaison with stakeholders; encourage and support a team approach to screening
- coordinate production of an annual report
- provide the public face of the program
- reports to the Director of Public Health

PEI PAP SCREENING PROGRAM

***Goal*:** to reduce the incidence and mortality rates of cervical cancer in PEI.

PAP AWARENESS WORKING GROUP
Terms of Reference

***Purpose*:**

- develop and implement a strategy to provide prevention education for the public and health practitioners

***Membership*:**

- membership will include representatives of PEI Medical Society, Public Health Nursing representatives, Canadian Cancer Society, and representatives from PEI Department of Health.
- ***Inaugural members*:**

  Chair: Mary Beth Roach, Social Marketing Consultant, DHSS.
  Holly Smith, CCS
  Kathy Mahar, Medical Society
  Jo-Ann MacDonald, PHN, DHSS
  Laurie Ann McCardle, Women's Network
  Heather MacMillan, Pap Screening Program Coordinator, DHSS

- ***Term:*** 2 year appointment, renewable.

***Reporting Relationship*:**

- the working group will report to the Pap Screening Advisory Committee,
- ad-hoc committees may be established to work on time-limited special projects,
- coordination will be provided by Pap Screening Program Coordinator,
- budget request and rationale must be submitted to Pap Screening Advisory Committee.

***Frequency of Meetings*:**

- the Pap Awareness Working Group will meet at least four times a year. Other meetings, teleconferences and e-mails will occur as necessary.

PEI PAP SCREENING PROGRAM

Goal: To reduce the incidence and mortality rates of cervical cancer in PEI.

PROGRAM PERFORMANCE INDICATORS WORKING GROUP
Terms of Reference

***Purpose*:**
- to evaluate the Pap Screening Program

***Membership*:**
- membership will include representatives of from PEI Department of Health and Social Services, researchers.
- ***Inaugural members*:**
  Chair: Linda VanTil, Epidemiology DHSS.
  Tina Pranger, Public Health and Evaluation, DHSS
  Heather MacMillan, Pap Screening Program Coordinator, DHSS.
- ***Term:*** 2 year appointment, renewable.

***Reporting Relationship*:**
- the working group will report to the Pap Screening Advisory Committee
- ad-hoc committees may be established to work on time-limited special projects
- coordination will be provided by Pap Screening Program Coordinator
- budget request and rationale must be submitted to Pap Screening Advisory Committee.

***Frequency of Meetings*:**
- the Program Performance Indicators Working Group will meet at least once a year. Other meetings, teleconferences and e-mails will occur as necessary.

PEI PAP SCREENING PROGRAM

Goal: to reduce the incidence and mortality rates of cervical cancer in PEI.

SCREENING GUIDELINES WORKING GROUP
Terms of Reference

Purpose:

- to develop guidelines for PEI Pap Screening Program.

Membership:

- membership will include representatives of from the PEI Medical Society, Family Physicians and Gynecologists, PEI Department of Health..
- ***Inaugural members:***

  Chair: Dr. Janet Baker, Medical Society.
  Teresa Hennebery, Public Health And Evaluation, DHSS.
  Nancy MacCallum, Chief Cytology Technologist
  Representative OBGYN
  Heather MacMillan, Pap Screening Program Coordinator, DHSS.
- ***Term:*** 2 year appointment, renewable.

Reporting Relationship:

- the working group will report to the Pap Screening Advisory Committee
- ad-hoc committees may be established to work on time-limited special projects
- coordination will be provided by Pap Screening Program Coordinator
- budget request and rationale must be submitted to Pap Screening Advisory Committee.

Frequency of Meetings:

- the Pap Awareness Working Group will meet as necessary, using meetings, teleconferences or e-mails.

PEI PAP SCREENING PROGRAM

Goal: to reduce the incidence and mortality rates of cervical cancer in PEI.

CYTOLOGY REGISTRY WORKING GROUP
Terms of Reference

***Purpose*:**

- to implement the cytology registry and procedures for follow-up of cervical cytology.

***Membership*:**

- membership will include representatives of from the QEH Laboratory, Cytology, and Information Technology (IT).
- ***Inaugural members*:**

  Chair: Dr. Marvin Tesch, Pathologist, QEH.
  Linda VanTil, Epidemiologist, DHSS
  Mike Devine, Queen's Region IT
  Heather MacMillan, Pap Screening Program Coordinator, DHSS.

- ***Term:*** 2 year appointment, renewable.

***Reporting Relationship*:**

- the working group will report to the Pap Screening Advisory Committee
- ad-hoc committees may be established to work on time-limited special projects
- coordination will be provided by Pap Screening Program Coordinator
- budget request and rationale must be submitted to Pap Screening Advisory Committee.

***Frequency of Meetings*:**

- the Pap Awareness Working Group will meet at least twice a year. Other meetings, teleconferences and e-mails will occur as necessary.

PEI PAP SCREENING PROGRAM

***Goal*:** to reduce the incidence and mortality rates of cervical cancer in PEI.

RECRUITMENT WORKING GROUP
Terms of Reference

***Purpose*:**

- to develop a provincial strategy to increase recruitment of women for Pap Screening.

***Membership*:**

- membership will include front-line providers, consumer representatives, Public Health Unit/Regions representatives, Canadian Cancer Society and representatives from other organizations that deal with recruitment of women for cervical screening, researchers, PEI Department of Health.
- ***Inaugural members*:**

  Chairs: Johanne Irwin, DHSS and Vicki Francis, PEI Division Cancer Society
  Dr. Janet Baker, GP
  Mae Gorrill, WP PHN
  Debra Harris, EK Health Center
  Rod Stanley, EP Community Relations
  Gloria Lea, SK PHN
  Representative from Women's Institute
  Representative from Advisory Council of Status of Women
  Heather MacMillan, Pap Screening Program Coordinator, DHSS.
- ***Term:*** 2 year appointment, renewable.

***Reporting Relationship*:**

- the working group will report to the Pap Screening Advisory Committee
- ad-hoc committees may be established to work on time-limited special projects
- coordination will be provided by Pap Screening Program Coordinator
- budget request and rationale must be submitted to Pap Screening Advisory Committee.

***Frequency of Meetings*:**

- the Recruitment Working Group will meet at least twice a year. Other meetings, teleconferences and e-mails will occur as necessary.

Appendix H: Detailed Data for Program Indicators

see Section 4

Participation Data (counts of women)

	one year: 2001		two years: 2000 to 2001		three years: 1999 to 2001	
age group	# women screened	# women in population[1]	# women screened	# women in population[1]	# women screened	# women in population[1]
<15	6	12708	10	13586	9	14332
15-19	652	5124	1111	5147	1588	5284
20-24	1958	4943	2914	5134	3538	5282
25-29	2105	4561	3118	4818	3547	5086
30-34	2297	4720	3264	4938	3694	5198
35-39	2371	5414	3617	5730	4072	5898
40-44	2410	5711	3633	5871	4023	6052
45-49	2202	5468	3255	5530	3528	5467
50-54	2064	5069	2963	5150	3241	5269
55-59	1638	4052	2219	3937	2307	3835
60-64	1147	3109	1591	3094	1685	3141
65-69	958	2839	1342	2898	1430	2888
70-74	610	2416	891	2453	1000	2515
75-79	388	2246	604	2277	703	2313
80-84	238	1915	343	1951	360	1982
85+	81	2164	129	2326	156	2451

[1] source: PEI Medicare Registry

2001 Cytology Results (count of Pap tests)

	NORM	LSIL	ASCUS	AGUS (reactive)	HSIL	AGUS (dysplasia)	Unsat	Other*
<15	0	0	0	0	0	0	0	6
15-19	684	19	13	0	0	0	3	0
20-24	2083	84	34	5	13	0	4	0
25-29	2288	60	41	11	33	0	6	0
30-34	2527	30	28	14	24	2	6	0
35-39	2497	21	25	9	12	1	5	0
40-44	2525	22	16	12	9	1	10	0
45-49	2257	13	20	13	7	0	2	4
50-54	2127	7	4	16	8	1	3	5
55-59	1688	0	5	13	4	0	1	6
60-64	1198	0	2	5	1	1	3	4
65-69	989	1	3	6	1	1	1	1
70-74	629	0	1	5	0	0	0	0
75-79	410	0	3	3	0	0	2	1
80-84	246	0	0	2	0	0	3	1
85+	78	0	1	3	2	1	0	0
Total	22232	257	196	117	114	8	49	22

* topography code in diagnosis field

NOTE: see Section 4 for description of Bethesda categories of cytology results

2001 Follow-up Recommendations

Laboratory Code	Count of Pap Tests
1.5	1114
6	282
12	19961
100	5
110	103
120	18
130	280
140	55
Missing	1177
Total	22995

Appendix I: Minimum Dataset for Cytology Registry

Epidemiology Export from LCMS (as of May 31, 2001)

Requires the ability to request a complete listing of all cytological or histological records for a user-defined period of time. This includes persons with no match in the registration file. Use of this export function will be restricted to sites within IHIS network.

For each pap test (defined by topography code=T-83), the fields exported are:

- Laboratory number
- patient name (first and last)
- PHN
- DOB
- sex
- date pap collected
- requesting MD code
- pathologist ID code
- cytotechnologist ID code
- recommended follow-up time
- date of cyto report
- diagnosis (Bethesda code)
- qualifier: coded reason for unsat smear/limited by (Bethesda code)

For each gynecological histology (defined by topography code=T80 to T-87), the fields exported are:

- Laboratory number
- designation of multiple samples from same patient
- patient name (first and last)
- PHN
- DOB
- sex
- date tissue collected
- requesting MD code
- pathologist ID code
- date of histo report
- procedure code (CCP)
- tissue site - topography code (SNOP)
- diagnosis - morphology code (SNOP)

In the future, the laboratory will provide notifications and export the following fields:

- *woman's PHN
- *date woman placed on MD's abnormal list
- *date of abnormal letter to woman
- *date woman placed on MD's normal overdue list
- *date of overdue letter to woman

Appendix J: Cytology Registy Upgrades

Functional Requirements of LCMS for Pap Registry
Identified by Cytology Registry WG, May 29, 2001

1. identify abnormal paps that are overdue for follow-up
   - HSIL and AGUS need subsequent histology
   - LSIL and ASCUS with LSIL/ASCUS in previous 2 years need subsequent histology
   - LSIL and ASCUS with none/NORM/UNSAT in previous 2 years need subsequent pap
   - NORM and UNSAT with LSIL/ASCUS in previous 2 years need subsequent pap

(see details in "Pap Smear Functionality" Feb 8, 2001)

2. use paps identified in (1) in a formatted physician list
   - overdue timeframe = 9 months
   - fields to be merged are predefined:
     patient name, PHN, Lab#, date of last pap, diagnosis
   - new field required to capture date woman placed on list; part of lab record (1)

3. use paps identified in (1) in a formatted letter to women
   - overdue timeframe = 12 months
   - fields to be merged are predefined:
     date, address, name, date of last pap, lab#, MD name
   - text of letter will require regular changes - these should not require programming, but should be done by the administrator (eg. name and signature on letter)
   - new field required to capture date woman sent a letter; part of lab record (1)

4. identify normal paps that are overdue for follow-up
   - exclude women with histo procedure= complete hysterectomy
   - exclude women <19 and >69 years of age
   - NORM and UNSAT need subsequent pap

5. use paps identified in (4) in a formatted physician list
   - overdue timeframe = 30 months if NORM
     = 15 months if NORM with any HSIL/AGUS in history
     = 15 months if UNSAT
   - fields to be merged are predefined:
     patient name, PHN, Lab#, date of last pap, diagnosis
   - new field required to capture date woman placed on list; part of lab record (4)

6. use paps identified in (4) in a formatted letter to women
   - overdue timeframe = 30 months
   - fields to be merged are predefined: date, address, name, date of last pap
   - text of letter will require regular changes - these should not require programming, but should be done by the administrator
   - new field required to capture date woman sent a letter; part of lab record (4)

7. identify women with no pap history
    - exclude women with histo procedure= complete hysterectomy
    - exclude women <19 and >69 years of age
    - exclude women sent this letter previously

8. use women identified in (7) in a formatted letter to women
    - fields to be merged are predefined: date, address, name
    - text of letter will require regular changes - these should not require programming, but should be done by the administrator
    - fields need to be exported to an ascii file for use by PEI Pap Screening Program:
        date woman sent letter (8)
        name
        address
        PHN
        DOB

9. accommodate smear taker that is not the family physician
    - require differentiation of:
        a) smear taker - needs smear quality report (may be a nurse)
        b) physician responsible for follow-up - needs initial report of results, physician lists (2) and (5)
        c) family MD if OBGYN responsible for follow-up - needs copy of initial report of results (for information)
    - currently a) and b) are identified by "requesting MD" field
        c) is identified by "copy to MD" field

Appendix K: Pap Screening Clinic

The goal of the Pap Screening Clinic is to increase the number of women regularly screened with a Pap test, by providing an alternative service to increase accessibility. The model Clinic is funded for period September 2001 to March 31, 2003. The objectives of the Clinic are to:

- Provide Pap test (with at least a 2 year interval between Paps) to
  1500 women in year one (50% capacity), and
  3000 women in year two (75% capacity)
- Have early identification of women at risk of cervical cancer
- Be a model for specialized preventive medical clinics
- Priovide resource material for pap and breast screening programs
- Have an independent evaluation of the clinic

Services provided at the clinic are described in Section 5.5

The remainder of this section includes:

- Guardian article from the press conference opening the clinic on September 6, 2001
- Guardian editorial on September 11, 2001
- Registration Form used by the Clinic
- Letter of Results mailed to women attending the Clinic
  - normal results
  - abnormal results
- Preliminary Evaluation of the Clinic

Pap-screening clinic opens in Cornwall

Health minister says clinic is a key initiative in reducing rate of cervical cancer among Island women.

BY JIM DAY
THE GUARDIAN

CORNWALL — Health Minister Jamie Ballem says a new Pap-screening clinic in Cornwall is a key initiative in reducing the rate of cervical cancer on Prince Edward Island.

The clinic opened Thursday in its permanent location at the Cornwall Medical Centre.

The opening follows a major public education program launched by government last year to raise awareness of the importance of screening.

Ballem believes more women are getting screened as a result of the campaign, which included frequent radio and television ads stressing that regular Pap screening can prevent cervical cancer.

On average, between eight to 10 Island women are diagnosed with this form of cancer each year.

Women who choose to be screened at the clinic will have their Pap test performed by a trained registered nurse under the supervision of Dr. David Stewart, a family physician.

"Having a registered nurse perform the Pap test provides another option for women who do not have a doctor or who for personal reasons would feel more comfortable with a nurse," said Stewart.

"The nurse will be able to answer questions about the Pap test as well as other preventative health practices like breast screening."

The clinic will be open three days a week including some evenings.

Stewart hopes at least 1,000 women will come to the clinic each year to be tested. He said the clinic could accommodate as many as 4,000 woman a year.

"Women are strongly encouraged to have a Pap test at least every two years as cervical cancer can truely be prevented with early detection," he said.

A Pap test detects very early cell changes which can be treated before cancer develops, said Diane Devitt, past president of the Canadian Cancer Society, P.E.I. division.

"With early detection, we can virtually eliminate deaths from cervical cancer," she said.

Results of tests done at the Pap-screening clinic in Cornwall will be forwarded to the clinic as well as to the woman's family doctor, Stewart said.

He said the family doctor will be responsible for following up on any abnormalities detected.

If a woman does not have a family doctor, Stewart will provide the followup of any abnormal Pap tests.

Women between the ages of 18 and 69 who have not had a Pap test in the last two years can now call the Pap Screening Clinic toll free at 1-866-818-7277 to book a test.

Ballem said his department will explore the possibility of going to other parts of the province with a Pap-screening clinic.

Opposition Leader Ron MacKinley applauded the initiative to open a Pap-screening clinic in his riding.

"This is a very important service for women on Prince Edward Island, and I am proud that the people in my home community took this on as a project," he said in a statement.

"They must be very proud of what they have accomplished, and I am pleased that their work has paid off."

GUARDIAN PHOTO BY JIM DAY

Dr. David Stewart, a family physician, will supervise the new Pap-screening clinic at the Cornwall Medical Centre. The goal of the Pap tests is to reduce the incidents of cervical cancer among Island women.

The Guardian

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Pap clinic small victory for health care

Making a vital service more accessible to Island women is a good example of how the health-care system can adapt.

Health care is a big, complicated topic that intimidates many people, especially with all the doom and gloom talk of the last few years and the rhetoric and confusion such talk produces.

It's difficult for most Islanders to know what to think about their health-care system which plays such an important role in their lives. On the one hand, the provinces are clamouring that Ottawa is squeezing them when it comes to sharing medicare costs. At the same time, the federal government counters that the provinces are flush with federal money, it is just that they aren't using the precious federal dollars properly.

But every once in a while a small ray of sunshine appears in our health-care system. Such was the case a few days ago when the provincial government announced the beginning of a new Pap-screening clinic.

It will be located in the Cornwall Medical Centre. Women who choose to be screened at the clinic will have their Pap test performed by a trained registered nurse under the supervision of Dr. David Stewart, a family physician. All they have to do is call the clinic to set up an appointment. Having a registered nurse perform the Pap test provides another option for women who don't have a doctor or who, for personal reasons, would feel more comfortable with a nurse than a male doctor.

The clinic will be open three days a week, including some evenings. Stewart hopes at least 1,000 women will come to the clinic each year to be tested. He said the clinic could accommodate as many as 4,000 women a year.

Let's hope the doctor's optimism comes true since cervical cancer is a serious health concern. On average, between eight and 10 Island women are diagnosed with this form of cancer each year. The good news is that with early detection, in most cases, the disease can be beaten.

Jamie Ballem, P.E.I.'s minister of health and social services, says his department will be keeping an eye on the Cornwall clinic. He says his department will explore the possibility of going to other parts of the province with a Pap-screening clinic.

The province is to be applauded for the new Pap-screening clinic. It's one of those initiatives that makes so much sense you wonder why someone hadn't thought of it before.

The clinic isn't the answer to our health-care problems, but it's a logical step forward in making the system more accessible to the public. After all, every journey starts with some small steps.

Registration Form used by Pap Screening Clinic:

Appointment date: _____

Pap Screening Clinic
Cornwall Medical Centre, PEI
1-866-818-7277(PAPS)

Name: _____

Address: _____ Postal Code: _____

Telephone: _____ - _____ Health Card Number: | | | | | | | | | | |

Date of Birth: _____
day / month / year

Family Doctor: _____

Date of Last Pap: _____

Have you had a hysterectomy? □yes □no If yes, date: _____
Reason for: _____

Do you still have a cervix? □yes □no □don't know
Do you have a mother or sister with ovarian cancer? □yes □no □don't know

I understand that my visit today will only include a Pap test at the Pap Screening Clinic. **This visit does not replace having a complete physical examination by my family doctor.** The results of my Pap test will go directly to my family doctor. The Pap Screening Clinic will also send a letter of my tests results to the above mailing address.

_____ _____
Signature Date

□ I give permission to be contacted for evaluation of this clinic.

Office Use Only: ☐Normal ☐LSIL ☐HSIL Date Results Received:

☐50-69 ☐letter sent Date GP office contacted:

Letter of Results (normal) mailed to women attending the Clinic:

PAP Screening Clinic
Cornwall Medical Centre, PEI
Phone: 1-866-818-PAPS (7277)

_____

Dear _____,

Thank you for attending the Pap Screening Clinic. I am pleased to report that your Pap test results were normal.

Your next Pap appointment should be in 2 years.

A few months before your next Pap test is due, please call your family doctor or the Pap Screening Clinic's toll free number, 1-866-818-PAPS (7277) to book your next appointment. If you require further information, please call your doctor or contact the Pap Screening Clinic.

If your address or phone number changes, please inform the Pap Screening Clinic of any changes.

Having regular Pap tests can greatly reduce your risk of cervical cancer. We are pleased that you are taking a preventive role in your health practice.

Yours truly,

Dr. David Stewart MD
Pap Screening Clinic

Doctor's Comments: _____

_____

_____

_____

_____

Letter of Results (abnormal) mailed to women attending the Clinic:

PAP Screening Clinic
Cornwall Medical Centre, PEI
Phone: 1-866-818-PAPS (7277)

_____

Dear _____,

Thank you for attending the Pap Screening Clinic.

Your last Pap test result showed an abnormality which requires further examination. Please be assured this may not mean that there is a serious problem. In the majority of cases, an abnormality does not suggest cervical cancer. However, additional assessment is important.

This letter has been sent to you to ensure you have been contacted by your family doctor about the results of your screening clinic Pap test. If you have not heard from your doctor, I encourage you to make contact to discuss your pap test results.

If your address or phone number changes, please let the Pap Screening Clinic know by calling the toll-free number 1-866-818-7277 (PAPS).

Having regular Pap tests can greatly reduce your risk of cervical cancer. We are pleased that you are taking an active role in your preventive health practices.

Yours truly,

Dr. David Stewart MD
Pap Screening Clinic

Doctor's Comments: _____

_____

_____

_____

_____

Preliminary Evaluation of Pap Screening Clinic

Preliminary evaluation of the Pap Screening Clinic used the period **September 12, 2001 to December 19, 2001**. The sources used for this evaluation included:

- Clinic Registration forms
- Clinic Appointment Book
- Laboratory results of Pap tests
- Telephone survey of 80 women that attended the clinic (91% of women attending the clinic agreed to be contacted for an evaluation)

Attendance:

The clinic was open three days a week, including Monday evenings. This provided a maximum capacity of 24 appointments per day, or 850 appointments during the period September to December 2001. A total of 569 appointments were booked (67% of capacity), with Tuesdays the most poorly attended. Women that canceled or rebooked were counted as 15% "no shows". This was a larger problem in the evening with 20% no shows, compared to 12% in the daytime. 21% of women attended an evening clinic; 10% of women surveyed preferred an evening appointment.

- A total of 477 women had a Pap test at the clinic; this represents 56% of capacity (Expected 50% of capacity to result in Pap tests)
- ALL women attending completed the registration form, whether they had a Pap or not
- Comparison of registration forms with lab results showed the clinic was unable to provide service to two women, including a disabled woman
- ALL women that had a Pap test were included in the shadow billing system

Women heard about the clinic by:

- Newspaper (47%)
- Word of mouth (27%)
- Pap Awareness Campaign (21%) (most often mentioned TV)

Women decided to call because:

- Increased awareness (43%)

  "Long time since last pap"

  "Needed to have it done"
- Preferred female (37%)
- Long waiting list for doctor (18%)
- Encouraged by friend (13%)
- Convenience (10%)
- No family doctor (7%)

Telephone Survey Questions

- How did you hear about the Clinic?
- What made you decide to call?
- Do you have a family doctor?
- Did you prefer a daytime or evening appointment?
- What did you like most? Least?
- Would you go back to the clinic?
- How would you rate the information you received about the Pap test?
- How would you rate having the Pap test?

Who attended the Pap Screening Clinic?

The age distribution of women attending was:

- 2% under 20
- 20% aged 20 to 34 years
- 32% aged 35 to 49 years
- 39% aged 50 to 69 years
- 7% aged 70 or older

This demonstrates that the majority of women attending were in the age range from 35 to 69. This is an appropriate distribution, since this age range has the lowest provincial screening rate (see Section 4).

Although the clinic was located in Queen's region, women attending the clinic resided in all PEI's Health Regions. The residence of the women attending was:

- 22% West Prince (includes women attending one O'Leary clinic)
- 14% East Prince
- 38% Queen's
- 3% Southern Kings
- 23% Eastern Kings (includes women attending one Souris Clinic)

Of the women that attended the clinic in Cornwall, 53% traveled from another region.

Medical history of women attending the clinic:

- 21% had a hysterectomy; 77% of these women no longer had a cervix

  "I don't have to go again because of hysterectomy, but at least now I know ; I was never told before."
- 12% had a previous abnormality on a past Pap test
- 3% had a family history of ovarian cancer
- 3% had an out-of-province Medicare number (recently moved or students)
- 7% saw Dr. DI Stewart at the clinic

When asked what they liked most about the clinic, women responded:

- Relaxed atmosphere (81%)
- Short wait time (39%)
- Preferred female (30%)
- Professionalism of staff (27%)

Overall, 93% of women attending would go back to the clinic.

When asked what they liked least about the clinic, only a small number of women responded, but they raised these issues:

- Not offered a full exam, so still need to see family doctor

  (Pap Screening Clinic was not designed to replace a full exam by the family doctor.)
- Lack of privacy

  (Pap Screening Clinic was designed to provide women with a letter of results, and provide a shard, relaxed waiting area.)
- Prefer call-backs for future appointments

  (Current clinic model is funded for two years which does not provide enough time for call-backs.)

Screening interval since the last Pap:

Screening interval of women attending clinic, determined by laboratory dates:

- 25% had last Pap within past 2 years
- 75% had last Pap 2 or more years ago
- 61% had last Pap 3 or more years ago
  (this is an improvement over the 40% seen at previous WWC, see Appendix D)
- 42% had last Pap 5 or more years ago

These intervals demonstrate the majority of women attending the clinic were overdue for Pap screening.

Screening interval of women attending clinic, determined by self-report dates:

- 7% reported a Pap within past 2 yr
  (most confirmed by lab)
- 31% reported a Pap within past 3 yr
  (but half had a Pap in past 2 years)
- 62% reported last Pap 3 or more years ago
- 16% could not recall date of last Pap
  (only 14% had a Pap in past 2 yr)

Screening Interval: Comparison of Self-report with Laboratory
(# women with x years since last pap)

Selfreport	Laboratory <1	<2	<3	<4	<5	5+ or never
<1	**5**					1
<2	5	**13**	2			8
<3	3	72	**25**	15	3	28
<4	1	7	25	**19**	4	15
<5	1	4	3	12	**13**	19
5+			6	8	11	**71**
unknown	5	6	3	3	4	57
	20	102	64	57	35	199

Pap Test Results:

Smear adequacy for the clinic:

- Satisfactory (940/1,000 Pap tests)
- Satisfactory, but limited (58/1,000 Pap tests)
- Unsatisfactory (2/1,000 Pap tests)

Smear adequacy was similar to provincial rates (see Section 4). The single unsatisfactory test was repeated.

- Women's satisfaction: 86% rated having the Pap test as "very good".

Cytology results:

- Normal (983/1,000 Pap tests)
- Low grade changes (18/1,000 Pap tests)
- High grade changes (0/1,000 Pap tests)

The rate of both low grade and high grade changes are slightly lower than the provincial rate (see Section 4).

Other results included infections, not related to cytology changes. Follow-up care was required by 2.5% of women attending the clinic:

- 9 women were referred to their family doctor for follow-up
- 2 women required follow-up care by Dr. DI Stewart.

Letters with results were mailed to all women within 10 days of receipt of the laboratory results. Women received either a letter of normal results, or a letter of abnormal results (see Appendix K). 90% of women were pleased to get a letter with their results. Some issues raised included:

- Wrong letter mailed (results were normal, but letter indicated follow-up needed)
- Letter did not mention other findings, such as infections or hysterectomy.
- *"I liked the letter. I used to wonder if the doctor actually saw the results. This way you have them right in front of you and you know."*

Recommendations[14]:

- ✔ The majority of women attending the clinic were overdue for Pap screening: 75% of the women attending had their last Pap two or more years ago.
- The use of the clinic by regularly screened women could be improved by asking women that are self-reporting their last pap in the past three years for both the year and month of their last pap test.
- ✔ Need for evening clinics is limited to one evening per week
- For women recently moved to PEI, delay appointment until PEI health number is assigned (3 months after move) to ensure valid PHN's are attached to laboratory results.
- ✔ Modify letters with results to allow comments for infections, hysterectomy.
- ✔ Modify letters with results to colour code the abnormal results letter
- Investigate alternative access for disabled women
- Reduced expected capacity for year two from 75% to 70% (this will require 85% of capacity to be booked for appointments when allowing for 15% "no shows")
- Improving awareness of the clinic needs to be in collaboration with the Program's communication plan
- Consideration should be given to scheduling clinics in other locations, since over half of the women traveling to the Clinic are from other health regions. This will require the Education and Recruitment Working Group to address issues such as funding, supervision, available equipment, and communication with physicians.
- Modify appointment book to include columns for:
  time of appointment, name and phone, attended/rebooked, hysterectomy, date results received, abnormal letter sent, date letter sent
- ✔ Clinic format provides an alternative access for many women; however the format is not suitable for women who require more privacy or who need a complete examination.

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14 ✔ indicates actions taken since January 1, 2002

Additional recommendations were learned as result of the Clinic, but apply to Pap screening across the province:

- ✔ One slide per patient is generated by the clinic, decreasing laboratory workload, supply and storage costs. With this practise as recommended by the laboratory, the clinic has maintained specimen adequacy rates and cytology results similar to the rest of the province.
- ✔ Suspected infections require submission of a **cervical swab** for culture and sensitivity; **vaginal wall swabs** are only to be submitted for Gr. B Strep or Bacterial Vaginosis screening of women under 54 years.
- Hysterectomy is a source of confusion that needs to be addressed by the Program's screening guidelines.
- Once screening guidelines are developed for the Program, laboratory recommendations of follow-up should be consistent with these guidelines
- Screening guidelines need to help physicians interpret laboratory terminology.